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The San Francisco AIDS Oral History Series

THE AIDS EPIDEMIC IN SAN FRANCISCO: THE RESPONSE OF THE NURSING PROFESSION,
1981-1984

Volume II

Gary Stephen Carr, R.N., Ph.D., F.N.P.-C. NURSE PRACTITIONER AT THE AIDS
CLINIC, SAN FRANCISCO GENERAL
HOSPITAL

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AIDS EPIDEMIC

With an Introduction by
Helen M. Miramontes, R.N., M.S., F.A.A.N.

Interviews Conducted by
Sally Smith Hughes, Ph.D.
in 1995 and 1996

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Gary Carr (b. 1948), nurse practitioner at AIDS Clinic, San Francisco General Hospital (SFGH): nursing for the gay community in New York, 1975-1980; initial contact with AIDS outbreak in San Francisco; comments on Paul Volberding, Donald Abrams, Bobbi Campbell, and Ward 86; medical definition of AIDS, ARC, opportunistic infections; marginal economic status of gay community, and SFGH role as primary provider; reflections on nursing and AIDS, anti-semitism at SFGH; work with AIDS drug trials, AIDS screening clinic. Angie Lewis, nurse educator and clinical nurse at UC San Francisco (UCSF): education, clinical work in obstetrics and gynecology; gay sex education at UCSF; June 1981 Bay Area Physicians for Human Rights (BAPHR) conference, talk on Kaposi's sarcoma (KS); comments on Volberding, Abrams, Campbell, Marcus Conant, Helen Schietinger and the KS Study Group; Lesbian/Gay Health Care Worker June 1982 Conference; early AIDS Foundation and Shanti work; issues of opportunistic infection, patient empowerment, patient confidentiality, press treatment of the disease; the impact of the AIDS epidemic on nursing.

Introduction by Helen M. Miramontes, R.N., M.S., F.A.A.N., Associate Clinical Professor, Community Health Systems Department, School of Nursing, University of California, San Francisco.

Interviewed 1995-1996 by Sally Smith Hughes, Ph.D., for the San Francisco AIDS Oral History Series. Regional Oral History Office, The Bancroft Library, University of California, Berkeley.

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SERIES INTRODUCTION--Helen M. Miramontes, R.N., M.S., F.A.A.N.

Nursing and medicine were confronted with very similar challenges in 1981 when HIV infection surfaced as a new unidentified disease in the gay communities of San Francisco, Los Angeles, and New York City. At that time it was not known whether this new phenomenon, named Gay-Related Immune Deficiency (GRID), was infectious and contagious, and if so, how it was transmitted. Were nurses, like physicians, at risk for becoming infected if they provided care, and would their families also be at risk for contracting this disease? There was much speculation and controversy as to the potential etiology of the new disease. Some people including members of the impacted gay community, proposed that this new disease was the result of recreational drug use, such as "poppers" (nitrates) and indiscriminate anonymous sexual activity, as demonstrated by the popularity of bathhouses in the gay community, and not due to an infectious organism. A few very knowledgeable physicians/disease specialists, such as Don Francis, hypothesized that this new disease was caused by an infectious agent, probably a virus, and transmitted by means similar to hepatitis B. There was a lot of fear among health care providers about contagion, but there was also significant prejudice and discriminatory behavior because the new disease was identified in a population (gay/bisexual men) that was stigmatized by the larger society. Identification of the disease in people of color, especially African Americans and injection drug users, only exacerbated the biases, prejudices, and discriminatory behavior.

Many nurses demonstrated the same attitudes, beliefs, and behaviors seen in the larger society. I was a critical care nurse working in an intensive care unit (ICU) in a large teaching facility of a health maintenance organization in Santa Clara county. In the early years of the epidemic, it was not unusual to have two to three patients with *Pneumocystis carinii* pneumonia on ventilators in the ICU at any one time. Because some nurses avoided taking care of these patients, several of us volunteered to care for them on a regular basis. Inappropriate infection control techniques by health care providers, such as wearing gowns, masks and gloves for simple, nontransmissible activities, were the norm rather than the rarity. There were frequent breaches in confidentiality, not only among nurses but also among other health care workers. Similar situations occurred in San Francisco facilities as well.

Fortunately, some nurses rose above their fears and volunteered on a regular basis to provide the care and support required to meet the needs of these very ill and frequently terminal patients. Nurses also participated in community activities and organizations that were established to respond to this new disease. They creatively utilized the skills and expertise developed in caring for patients/clients in

traditional settings, such as hospitals, clinics, and homes, to establish programs in community-based organizations. I saw nurses training volunteers to provide practical and emotional support, educating their peers and the public about the disease, advocating for compassion and resources, working with families impacted by this disease, and participating in policy development and political action that was vital to enhancing community response to this growing epidemic. Some of these nurses were also members of the at-risk community; others had family or friends as members of the gay community, and others became involved as a response to the hysteria and fears within the health care environment. But all demonstrated core values of nursing compassion and care.

Individual nurses, such as Cliff Morrison, Helen Schietinger, Gary Carr, and others, did not hesitate to become proactive, not only in care, but also in advocacy. These nurses did not wait for the nursing organizations to initiate a response to the epidemic. In fact, it was individual nurses who pressured and guided the nursing associations to develop position statements, to provide testimony before legislative bodies, and to mount positive responses concerning the epidemic, educating nurses as well as the public. Traditional nursing organizations, like traditional medical organizations, were not only hesitant, but resistant to becoming aggressively involved in the epidemic. It was a few nurses within the California Nurses Association who provided much of the expertise in education and training that formed the foundation of a very successful statewide education and training program for providers funded by the state for ten years. And it was these nurses who also lobbied for funds and provided expert testimony on numerous pieces of state legislation. These California nurses also provided leadership at the national level with the American Nurses Association on federal legislation. Some of these nurses provided leadership in clinical settings as well.

It was Cliff Morrison, as a clinical nurse specialist at San Francisco General Hospital, who designed and implemented a special unit for people with AIDS (Pas). This special unit, with integrated treatment, care, and support services, became the "gold standard" for inpatient care and was duplicated across the country. Later Cliff became the deputy director of a large Johnson & Johnson Foundation grant that successfully implemented HIV/AIDS care systems, similar to the San Francisco model, in eleven cities across the country.

Nurses also implemented other services in San Francisco community-based organizations. One of the nurses, Helen Schietinger, established the housing program of the Shanti Project. These early models of nurses responded creatively and effectively to the needs of the statewide nurse case manager for home care developed in the mid-1980s by a nurse, Peggy Falkner, in the State Health Department Office of AIDS. The Ward 86, San Francisco General Hospital, Outpatient Clinic is world renowned for

the quality of care and the expertise of its staff, many of whom are nurse practitioners like Gary Carr. UCSF AIDS Clinic has also has highly qualified nurse practitioners. Nurses were and are also significantly involved in AIDS Drugs Clinical Trials, including the San Francisco Community Consortium headed by Donald Abrams, M.D.

Nurses have always been involved with the poor and most vulnerable of a society's citizens. Each war, epidemic, and community disaster has had nurses in the middle of the crisis, providing a variety of services, care, and support. The AIDS epidemic is no different. In fact, in the early years before there was effective treatment, the caring of nurses was too often all that we could give. Often these nurses are not identified in the media or the history books; they are the "unsung heros." But it is often the nurse who sits with the patient and/or the family through the many critical episodes of AIDS; who counsels a person just receiving the positive results of an HIV test; who holds the hand of a dying person at night; who embraces a mother crying over the death of a son or daughter.

Some of us believe that everything in our professional lives, and sometimes our personal lives, has led us to this pandemic. The work has become a mission and we are committed to the long haul. Unfortunately, as of March, 1999, there appears to be no end in sight. The worldwide pandemic continues to rage out of control with 90 percent or more of new infections occurring in developing countries in Africa and Asia at the rate of 16,000 new infections per day. In some countries in the southern regions of Africa, 20 to 30 percent of the general populations are already infected. In this country, annual new infections have remained unchanged for several years and therapeutic drug treatments are not accessible to everyone who is infected. The need for nurses and nursing care continues to be vital and critical to our overall social response. Nurses will continue to participate and to use those nursing values and skills that best meet the need of people infected and affected by HIV/AIDS.

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March 1999
San Francisco, California

SERIES HISTORY--by Sally Smith Hughes

Project Origin

The idea for an oral history series on the medical impact of the San Francisco AIDS epidemic originated with Evelyne and David Lennette, virologists who have been following the history of the disease since its first recognition in 1981. In 1991, they began generously to provide support for interviews with physicians at the University of California, San Francisco [UCSF] and San Francisco General Hospital [SFGH] who were prominent in AIDS medicine in its earliest phase, 1981-1984. That series with twelve physicians, two dentists, and one epidemiologist is now complete and available for research at the Bancroft and UCSF libraries.

The physicians' accounts made evident the critical role of nurses in AIDS history. It seemed imperative to capture their story. In 1994 we applied for and received a two-year award of \$60,000 from the University of California Universitywide AIDS Research Program to interview ten nurses active in AIDS nursing in San Francisco. We gratefully acknowledge UARP's support of phase 2 of the AIDS oral history project. Jointly sponsored by the Regional Oral History Office of the Bancroft Library, UCB, and the Division of the History of Health Sciences, UCSF, it significantly expands oral documentation of the AIDS epidemic. As in the earlier series, the focus is on the first three years of the epidemic when San Francisco led the way in many areas of AIDS nursing and medicine.

Primary and Secondary Sources

To prepare for the interviews, I used the documents and publications described in the "Series History" essay appearing with the phase 1 oral histories. In addition, interviewees in the nurses series in several cases provided documents from their personal files which added immeasurably to the oral account. I wish particularly to thank Angie Lewis, Grace Lusby, Michael Helquist, and Helen Schietinger for the time they took to select, compile, and donate documents for the historical record. These documents will be deposited in the AIDS History Project Archives at UCSF Library.

The Oral History Process

The oral history methodology used in this project is that of the Regional Oral History Office, founded in 1954 and producer of over 1,400 archival oral histories. The method consists of background research in

primary and secondary sources; systematic recorded interviews; transcription, editing by the interviewer, and review and approval by the interviewee; deposition in manuscript libraries of bound volumes of transcripts with table of contents, introduction, interview history, and index; cataloging in national on-line library networks (MELVYL, RLIN, and OCLC); and publicity through ROHO news releases and announcements in scientific, medical, and historical journals and newsletters and via the UCSF Library web page (<http://www.library.ucsf.edu/>). The reader interested in the pros and cons of the oral history method is referred to the "Series History" in the AIDS physicians volumes.

Oral histories in the AIDS nurses series ranged in length from two to ten hours. Details of the interview process with specific individuals may be found in the interview history preceding each oral history transcript. The oral history volumes, tapes, and supporting documents will be available for research in the AIDS History Project Archives at UCSF Library.

Emerging Themes

ROHO's AIDS series consists to date of twenty-five oral histories on the medical and nursing response to the San Francisco AIDS epidemic in its first three years. There is a wealth of information on its medical, scientific, political, social, and personal aspects. Although it is impossible to do justice to this collection in a brief summary, the following comments suggest in broad outline the richness of the thematic material.

These oral histories with nurses continue the themes running through the physicians series--individual "preparedness" for the epidemic in both professional and personal senses; organizing medical, nursing, and social services in the face of a new and fatal disease; the epidemic's impact on the careers and emotional life of health care providers. Compared to the oral histories with physicians in phase 1, what is generally different about the oral histories with nurses is their portrayal of a day-to-day, hands-on, in-the-trenches engagement with the people most affected by the epidemic--the people with AIDS. Some of this distinction is due to the different requirements of the two professions. Put simplistically, physicians diagnose, treat, and prescribe for patients on an episodic basis. Their contact with patients, particularly in an incurable disease such as AIDS, may run for years, even decades, but is broken up into episodic bedside, clinic, or office visits.

Such is not the case with hospital nursing. As long as the patient is hospitalized, a nurse or nurses is caring for the patient in an immediate, personal, and ongoing fashion. The highs and lows of the nurse-patient relationship are difficult to escape, as these oral

histories indicate. Because nursing contact with patients tends to be more sustained and personal than is physicians', it is often more of a struggle to sustain a proper balance between personal involvement and professional detachment. Some of the nurses in these volumes speak of "burnout" as a consequence of over-commitment and of the measures they take to lessen or escape it.

The role of the gay community in AIDS activities is another persistent theme. The fact that six of the ten interviewees in this series are gay or lesbian is not incidental. In most cases, their sexual orientation was a basis for their original engagement in the epidemic, which to this day in San Francisco affects gay men in larger numbers than any other single demographic group. AIDS in the years covered by this project was widely perceived as a "gay" disease. The nurses in this series had the same perception and in many cases chose AIDS care as a way of assisting members of "the community", meaning the articulate and organized gay and lesbian community centered around, but not limited to, Castro Street in San Francisco. Thus it is inevitable, as these oral histories vividly demonstrate, that the history of AIDS in San Francisco, is inextricably intertwined with gay culture.

Yet another important theme is the impact of the epidemic on the stature of nursing. Although AIDS in San Francisco has always been a multidisciplinary activity, involving health care professionals, social and community workers, government agencies, etcetera, the interviews show nurses taking on more responsibilities, devising innovative services for holistic AIDS care, and assuming a stronger "voice" in the medical hierarchy. For example, it was nurses who organized and ran (of course with physician oversight), and continue currently to run the inpatient AIDS unit, Ward 5B (now 5A), at San Francisco General Hospital. Nurses also played a major role in structuring comprehensive patient management and community support systems which are a critical part of the multidisciplinary model of AIDS care for which San Francisco was known in the early epidemic. I hope the reader will be prompted to read on and to take from these oral histories much more than I have suggested here.

Locations of the Oral Histories

The oral history tapes and bound volumes are on deposit at UCSF Library's AIDS History Project Archives. The volumes are also available at the National Academy of Medicine, the Bancroft Library, UCLA, and other manuscript libraries.

Acknowledgement

We are grateful to Helen Miramontes, Associate Clinical Professor in the Community Health Systems Department at UCSF School of Nursing, for writing the introduction to the oral history series. Ms. Miramontes has been involved with AIDS activities at the federal state, and local levels. At UCSF, she served as Deputy Director of the International Center for HIV/AIDS Research & Clinical Training in Nursing. In 1996, she was named to the Presidential Advisory Council on HIV/AIDS.

We gratefully acknowledge the support of University of California Universitywide AIDS Research Program, award # R94-SF-083.

Note Regarding Terminology

In this project, both interviewer and interviewee sometimes use the term "AIDS" to refer to the disease before it had been officially given this name in the summer of 1982. "AIDS" is also used to designate the disease which in recent years has come to be known in scientific and medical circles as "HIV disease". In these oral histories, the term "AIDS" has been retained, even when its use is not historically accurate or in tune with contemporary technical terminology.

Sally Smith Hughes, Ph.D.
Research Historian and Project Director

July 1998
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THE SAN FRANCISCO AIDS ORAL HISTORY SERIES

PHASE 1: THE MEDICAL RESPONSE, 1981-1984

VOLUME I

Selma K. Dritz, M.D., M.P.H., "Charting the Epidemiological Course of AIDS, 1981-1984"

Mervyn F. Silverman, M.D., M.P.H., "Public Health Director: The Bathhouse Crisis, 1983-1984"

VOLUME II

Donald I. Abrams, M.D., "The KS Clinic, Lymphadenopathy and AIDS-Related Complex, and the County Community Consortium"

Marcus A. Conant, M.D., "Founding the KS Clinic, and Continued AIDS Activism"

Andrew A. Moss, Ph.D., "AIDS Epidemiology: Investigating and Getting the Word Out"

VOLUME III

Arthur J. Ammann, M.D., "Pediatric AIDS Immunologist: Advocate for the Children"

Paul A. Volberding, M.D., "Oncologist and Developer of the AIDS Clinic, San Francisco General Hospital"

Constance B. Wofsy, M.D., "Infectious Disease Physician, AIDS Educator, and Women's AIDS Advocate"

VOLUME IV

Donald P. Francis, M.D., D.Sc., "Epidemiologist, Centers for Disease Control: Defining AIDS and Isolating the Human Immunodeficiency Virus (HIV)"

Merle A. Sande, M.D., "Infectious Disease Specialist: AIDS Treatment and Infection Control at San Francisco General Hospital"

John L. Ziegler, M.D., Ph.D., "Oncologist: Kaposi's Sarcoma and AIDS Research in San Francisco and Globally"

VOLUME V

Herbert C. Perkins, M.D., "Director, Irwin Memorial Blood Bank: Transfusion AIDS and the Safety of the Nation's Blood Supply"

VOLUME VI

Deborah Greenspan, D.D.S., D.Sc., "Oral Manifestations of AIDS"

John S. Greenspan, D.D.S., Ph.D., "AIDS Specimen Bank, UCSF"

IN PROCESS

Jay A. Levy, M.D., Virologist, UCSF: Isolation of the AIDS Virus

Warren Winkelstein, Jr., M.D., M.P.H., The San Francisco Men's Health Study, UC Berkeley

PHASE 2: THE RESPONSE OF THE NURSING PROFESSION, 1981-1984

VOLUME I

Michael J. Helquist, "Journalist of the Early AIDS Epidemic in San Francisco"

Jeannee Parker Martin, R.N., M.P.H., "The AIDS Home Care Program of Visiting Nurses & Hospice of San Francisco"

Helen K. Schietinger, R.N., M.F.C.C., "Nurse Coordinator of UCSF's First AIDS Clinic"

VOLUME II

Gary Stephen Carr, R.N., Ph.D., F.N.P.-C., "Nurse Practitioner at the AIDS Clinic, San Francisco General Hospital"

Angie Lewis, R.N., M.S., "Nurse Educator in the San Francisco AIDS Epidemic"

IN PROCESS

Gayling Gee, R.N., M.S., Clinical Nurse at the AIDS Clinic, San Francisco General Hospital

Diane Jones, R.N., Staff Nurse at the AIDS Clinic, San Francisco General Hospital

Grace Lusby, R.N., Infection Control Nurse, San Francisco General Hospital

Diane Miller, Director of Hospital Planning, San Francisco General Hospital

Clifford Morrison, M.S., M.N., R.N., F.A.A.N., AIDS Clinical Coordinator, San Francisco General Hospital

PHASE 3: THE RESPONSE OF COMMUNITY PHYSICIANS, 1981-1984 (ALL IN PROCESS)

Ric Andrews, M.D., Psychiatrist

Robert Bolan, Jr., M.D., General Practitioner

James Campbell, M.D., Internal Medicine

Stephen Follansbee, M.D., Infectious Disease Specialist

James Groundwater, M.D., Dermatologist

Paul O'Malley, M.D., Communicable Diseases

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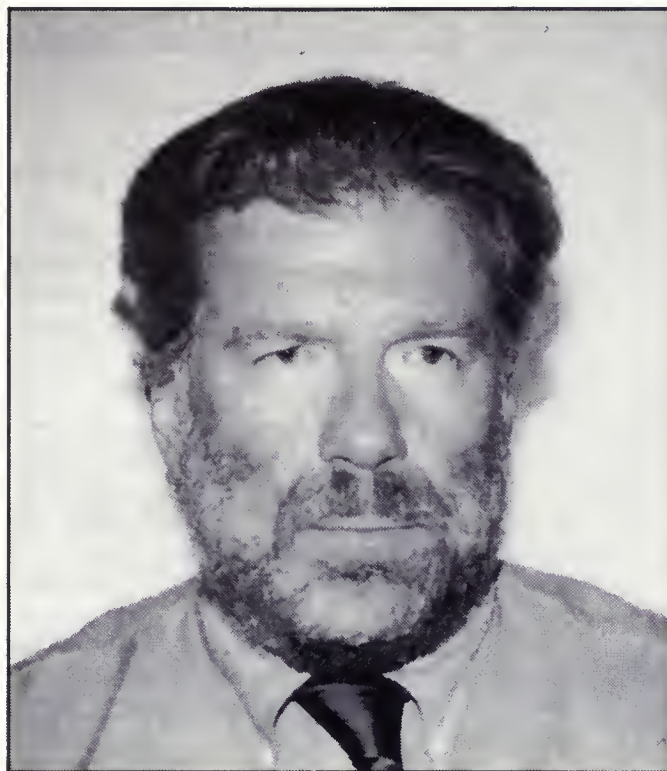
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THE SAN FRANCISCO AIDS EPIDEMIC: THE RESPONSE OF THE NURSING PROFESSION,
1981-1984
VOLUME II

Gary Stephen Carr, R.N., Ph.D., F.N.P.-C.

NURSE PRACTITIONER AT THE AIDS CLINIC, SAN FRANCISCO GENERAL HOSPITAL

An Interview Conducted by
Sally Smith Hughes, Ph.D
in 1995 and 1996



Gary Carr.

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INTERVIEW HISTORY--by Sally Smith Hughes, Ph.D.

Gary Carr was interviewed for the AIDS nurses oral history series because of his long service as nurse practitioner in the AIDS Clinic at San Francisco General Hospital [SFGH]. The clinic, which opened in January 1983 under the direction of Paul Volberding, was established to provide ongoing and comprehensive care to people with AIDS. It and the inpatient AIDS ward at SFGH eventually supplanted the Kaposi's Sarcoma Clinic at UCSF, founded in the summer of 1981, as the primary university sites for AIDS treatment in San Francisco.

As he relates in this history, Carr began work at the AIDS Clinic in December 1983. He recalls having to navigate construction debris as Gayling Gee, the clinic nurse, showed him around the as yet unfinished clinic. Carr came to the job with professional and personal experience that was to prove significant for his career in AIDS nursing. He had worked for several years in a clinic in New York City which provided medical services to gay men, and had then gone on to earn credentials as a nurse practitioner. This practical background, his concern for gay issues, and his warm, intense, and giving personality fitted him admirably for the professional and personal demands of AIDS nursing.

Carr's oral history naturally centers around the AIDS Clinic, which he describes from virtually every aspect--physical layout, staffing, nurse practitioner protocol, and so on. He also comments on the various ways in which AIDS was defined in the early days, and how functional definitions used in the clinic differed from official definitions of AIDS by the Centers for Disease Control. A sensitive and gentle personality, he also tells of his reactions to early patients, the fear and stigma associated with AIDS, and attitudes towards dying patients. He is intent to define the role of the nurse practitioner, and the pleasure and pride he experienced when physicians gave him the autonomy to make statements and decisions regarding patient care:

Carr: ...my most specific, vivid memory of my first day at work [at the AIDS Clinic], on Monday December 5, 1983, was Paul Volberding saying to me, "Use the words AIDS and cancer. Use the words...."

Hughes: Why did he instruct you in that way?

Carr: He was giving me the authority, the judgment, the recognition to tell people. For a nurse practitioner in those days, that was still a big deal. There's a long history in nursing, you're not supposed to tell the diagnosis. It was a big change, it was a big deal, it was a big part of what made it heady, that from the first day, I had the authority to talk to patients as an autonomous

health care practitioner, not as being under anybody else.
It was a big deal, Sally.

The Oral History Process

Two interviews were conducted on December 14, 1995 and January 9, 1996 at the comfortable apartment in the Sunset District which Carr shares with his partner. Carr was animated and fully engaged in the interview process, and was thoughtful and forthcoming in his answers. He reviewed and returned the transcripts with a few editorial changes.

This oral history provides an intimate view of the detailed operations of one of the first and foremost AIDS clinics in the world and of the personal trials and triumphs of one employed there almost from the clinic's inception. At the time of the interviews, Carr, in addition to his position at the AIDS Clinic, was a doctoral student at the UCSF School of Nursing and was due to assume a position on the University of San Francisco nursing faculty in January 1997. We are fortunate to have recorded this personal history while Carr's career in the AIDS Clinic was fresh in his mind.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Sally Smith Hughes, Ph.D.
Research Historian and Principal Editor

July 1998
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name GARY CARR, RN, PhD
Date of birth 7/7/45 Birthplace New York, N.Y.
Father's full name Joseph T. Carr
Occupation photography Birthplace Chicago, Ill
Mother's full name Etta P. Carr
Occupation Math teacher Birthplace New York, NY
Your ^{partner} spouse Matthew G. Chapman
Occupation Stock Exchange Birthplace Washington DC
Manager
Your children none

Where did you grow up? New York; Mount Vernon, N.Y.
Present community San Francisco
Education BSN, 1978; MSN, 1982; PhD (nursing),
1997.

Occupation(s) Nurse Practitioner, Asst. Pro-
fessor of Nursing
Areas of expertise HIV/AIDS; qualitative research

Other interests or activities Motorcycling, outdoors
activities, international travel,
gardening.
Organizations in which you are active Jewish Family + Children's
Services; ANAC.

INTERVIEW WITH GARY CARR

I FAMILY BACKGROUND AND EDUCATION

[Interview 1: December 14, 1995] ##¹

Family Background

Hughes: Let's start with where you were born and educated.

Carr: I'm forty-seven years old. I was born in New York City July 7, 1948. My family background is Jewish and moderately Orthodox and religious. My grandparents were all born in Eastern Europe. I grew up with them very much around and with the traditions, with the Yiddish language, stuff like that. When I was six years old, we moved from the Bronx to the suburbs, and sometimes when I joke about it, I say that was the year I came to America.

Education and Early Experiences

Carr: I went to public high school and college in Mount Vernon, New York, a suburb of New York City in Westchester County, just north of the city. It was still an environment that was almost completely Jewish and Catholic and with grandparents born in the old country.

I went to SUNY [State University of New York at Albany] from 1966 to 1970 and majored in English. After college, I spent a couple of years knocking around and traveling, spent a long period of time in Europe, and spent a long period of time in San Francisco. And then after I worked in advertising agencies in midtown Manhattan in New York--a Madison Avenue kind of thing--for

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

about two years in my early twenties, and that just seemed very vacuous. So I went back to school [Long Island University] part-time in the mid-seventies [1978] and became a registered nurse. I went to school part-time and worked part-time in Macy's.

Early Nursing Experiences

Attraction to Nursing

Hughes: What drew you to nursing?

Carr: I had started volunteering at a community-based clinic called the St. Mark's Community Clinic on the Lower East Side of New York,¹ and I'd say it was the New York equivalent of the Haight-Ashbury Clinic in those days. I had started volunteering there, and I got interested in health care.

I was involved with people who were politically part of the new left, as many of us were in those days. We had this critique of power and privilege, and medicine as a privileged thing. So I deliberately became a nurse, because I thought it was more based in the working class and less privileged. I have never regretted that decision. I liked nursing the minute I hit the ground, and I have always liked it ever since.

Hughes: What particularly do you like about it?

Carr: It's a nice combination of being very professional and very earthy at the same time. One of the things to like is that there are so many different things you can do that are nursing. But you're really there with people and human experience and human problems and coping. You're really there with it all the time, so much so that it can be exhausting. And you're able to get jobs that are interesting and keep you stimulated and where you believe what you're doing really makes a difference. And in terms of the world of work and the way things are now, that's no small thing. That's something not to be taken for granted. I've had the privilege of always having it.

So then I worked as a staff nurse in New York City for a few years as a surgical staff nurse at Mount Sinai Hospital, 1978-1980; per diem staff nurse, Bellevue Hospital, 1980-1981, and I

¹ Carr was on the clinic's board of directors 1974-1980.

had mentioned volunteering at the St. Mark's Clinic. While I was working on my nursing degree, my B.S.N., and afterwards while I worked as a staff nurse, I continued to work and intermittently have paid part-time positions at that clinic.

Providing Nursing Services for Gay Men, 1975-1980

Carr: We had one evening a week from 1975 to 1980 that was gay men's night. We tried to have an all gay male staff of volunteer physicians and nurses, and the clinic was specifically available for gay men. This was in the seventies, so HIV didn't even exist. We also had a night for lesbians with an all-women staff, and the collective that ran the clinic was both gay men and lesbians. And it was not only for people who were gay, but it was a big gay presence.

We didn't only have clinics for people who were gay; those were just specialty clinics. We also had a general community-based clinic. I always liked the politics of having people in the community knowing they were coming to a clinic run by gay people.

Around 1980, the clinic was sort of biting the dust and my personal life wasn't going so well. I was having problems with loneliness and isolation living in New York where everybody lives in a tiny little box and people are very isolated from each other. So in the spring of 1980, I left New York. I spent the summer of 1980 as a summer camp nurse on the Jersey shore in a Jewish camp where all the children were physically disabled, and that was really fun. That was a direction I might have considered going off in, in nursing, if other things hadn't happened.

Nurse Practitioner Education, 1980-1982

Carr: Then in the fall, I moved out to the country on Long Island and I spent the '80-'81 school year living in the dorms at SUNY at Stony Brook sixty miles out on Long Island. I think I was about thirty-two. I was by far the oldest person in the dormitory, although in the medical and nursing programs, as always, there were people of all ages. I took the first year of medical school--this was part of the program--as a nurse practitioner student. From '80 to '82, I worked on my master's degree in nursing at Stony Brook. The first year consisted of taking the entire first year of medical school with the medical students, except for the genetics course.

Hughes: Is that unusual?

Carr: Yes, most N.P. [nurse practitioner] programs have their own science curriculum. The one in Stony Brook was very new, but that was a neat thing to do at the time. The second year was clinical electives, and I spent the first half of the year doing clinical electives in New York City hospitals, clinics, and emergency rooms as a student nurse practitioner, mostly Queens Hospital in Jamaica, which was very interesting, very multicultural.

II THE AIDS EPIDEMIC

Pre-1981 Cases

Hughes: Now, in any of these medical settings, were you seeing cases that later would have been labeled AIDS or AIDS-related?

Carr: I was going to mention that in the late seventies in my last days at St. Mark's, I was seeing bizarre things in sexually active gay men that I now realize in retrospect were early manifestations of HIV, but we had no idea what they were. Things like genital warts, molluscum, shingles--things that anybody could get--would start to get worse. We'd see them worse and more persistently. I realize now that those people probably had HIV.

Hughes: Was it apparent enough that this was a subject of conversation?

Carr: At the time, yes.

Hughes: And did people wonder why there seemed to be this upsurge?

Carr: Yes, people talked about it. The dermatologists were very involved in it at that time, with that sense of, Something is weird here.

I remember in 1979 representing the St. Mark's Clinic at a conference on gay STDs [sexually transmitted diseases], a nationwide conference in Chicago. King Holmes, a physician from Seattle who I think is now a professor of infectious diseases at the University of Washington--I think at the time he worked for the county public health department in Seattle--said at the meeting, "Something bad is happening," or is going to happen, or is starting to happen, "with gay men who have a lot of sex." We called him homophobic and stuff like that. [laughter]

Hughes: He was noticing an upsurge in Washington?

Carr: I don't know whether it was locally in Seattle, or whether he was noticing it around the country. He was in a position to have a national perspective even at that time.

I was involved in a study back in the seventies of anal warts, anal gonorrhea in gay men. There were a lot of physicians, and even a lot of ID [infectious disease] physicians, who wouldn't acknowledge that men could get gonorrhea in the rectum. And this is why we felt that health care geared to the gay community was important. It wasn't that they got other diseases; it was just that people got STDs more frequently. There were a lot of quarters of society and places people had to go to access treatment where there was a very judgmental attitude. So we thought of it in political terms a lot. We used to say, "Treatment for a cold is better if you don't have to be afraid to let your partner hold your hand while you get it." Stuff like that.

We, the group of gay men in that clinic, in a way were very far ahead of our time. We were influenced by the Women's Health Collective in Boston that wrote Our Bodies, Ourselves, and we used to have meetings of gay men. We used to talk about doing self-exams with anuses, and we used to examine each other and stuff like that. The seventies were so outrageous. [laughs]

Hughes: Was there any scientific basis for thinking rectal gonorrhea was impossible?

Carr: No, it was homophobia, to say that it didn't exist.

Hughes: Because then you could dismiss a whole segment of the population.

Carr: I don't know why people said that. Either that, or people just couldn't conceive of that particular sexual act. It was not my interest to find out. [laughter]

In the first half of my second year in Stony Brook, as I said, I did rotations in New York City hospitals as a student nurse practitioner.

The second half of that year, and it was from February or March of '82 until the end of the summer, September '82, I went to Israel as a Stony Brook exchange student, and I worked in a small town in the desert in Israel with Jewish immigrants from Africa and Asia. It was a wonderful cultural experience.

The point is, I had worked in gay health care. I dropped out for a while, knowing I was dropping out temporarily, when AIDS didn't exist yet, and when I came back, it was there. So I had this window of being abroad and being totally out of touch and not talking to anybody in the States, and then when I came back the epidemic had hit.

Hughes: When did you come back?

Carr: September of '82. I had pulled up my roots for two years to go to Stony Brook, and I just wasn't quite ready to go back to Manhattan. The clinic I had been working in really had changed and gotten more authoritarian. Physicians had more power and nurses didn't so much any more, so I wasn't that interested in going back there. I was looking for a niche to work in health care in the gay community.

Staff Nurse, Trauma Unit, SFGH, 1982-1983

Carr: So in October '82, I came to San Francisco to stay with an old college friend, also a nurse, who was living in Bernal Heights and working as a staff nurse at SFGH [San Francisco General Hospital]. I took a job at SFGH where I stayed for about a year in the trauma unit. It's called 4D. The head nurse, then Susan Ilnicki, is still there, and we're sort of friends. And the reason I did it was because in New York in the seventies, I had worked in the trauma unit--the equivalent unit in Bellevue. There are ways those two hospitals are a lot alike.

So I said to her, "I've just finished my master's degree, and I'm certified as a nurse practitioner. I probably won't stay here that long." And she said, "That's okay. I mostly take new graduates, and I have to break them in a lot. I won't have to break you in a lot, so that's a fair exchange." So I ended up working there for about a year.

While I was working there, they started bringing in gay men with mysterious pneumonia, so that's why all of that history leads up to the AIDS epidemic. So it's a coincidence that I was in San Francisco. My being here had nothing to do with the epidemic. I just wasn't quite ready to go back to living in New York after living first in the country for a year on Long Island and then in the little town in the desert in Israel for six months.

Hughes: Was your idea that you would work in the trauma unit for a time and then return to New York?

Carr: Yes. Well, the purpose of working in trauma units in New York, knowing it wasn't what I wanted to do in the long term, was I thought it would be the place where I would get the most concentrated experience of being a nurse. [laughter] And the reason for doing it in San Francisco was just that that head nurse was willing to take me on, because I had worked on a similar unit, knowing that I wasn't going to work as a staff nurse for long.

Anti-Semitism

Carr: When I came to San Francisco, they actually singled me out for the critical care training program, and I didn't do very well in it at all. I encountered an enormous amount of anti-Semitism, and it was really the first time that had happened to me, and I was very shocked by it. The teacher apparently didn't know I was Jewish, and she made a couple of remarks in front of the group of trainees where she pointed out that somebody on the staff was Jewish in a way that was completely unnecessary and bizarre.

Then when I was working in one of the critical care units with one of the staff nurses as my preceptor, I told her I had just come back from Israel, and later the teacher came over to me and said, "Are you Jewish?" and I said, "Yes." And she said, "What, did you steal your name?" The next time I was in training, she totally failed me on everything I did that day and gave me very bad grades. So I left that program and went to being a staff nurse.

When Ward 86 was starting,¹ why I also was very anxious to leave that hospital. Later, when the position of the clinical nurse specialist on the AIDS unit [Ward 5B] was started, the job that Rita Fahrner had at first and has now, Cliff Morrison offered me the job, and I said no, because after that experience, I did not want to go back to working in the inpatient hospital. I've always had mixed feelings about that. In many ways, I would have liked that job, but I was so horrified by that hospital.

Hughes: It's not the image that one normally has of the General.

Carr: No, that's true. Ward 86 was a way to be there and not be there, both at the same time. You were on the UC payroll, which made you safe from those people, instead of the county payroll. And--I

¹ Ward 86, the AIDS Clinic at SFGH, opened in January 1983 in a building distinct from the hospital.

don't know how to say this--under the protection of Paul Volberding, who is somebody whose integrity you can trust.

The AIDS Clinic at San Francisco General Hospital

Hiring as Nurse Practitioner

Carr: In the early days, there was a patient, a Jewish man named Mark. I can't think of his last name. He was the one who wore the crown and said, "Phooey on AIDS" at a big public rally.

Hughes: Feldman.¹

Carr: Yes, I think so.

One morning in July of '83, I was listening to the AM all-news radio station while I was making the beds on my way out of 4D at the end of the night shift in the morning, and they said that he had died, and I felt so sad that instead of going home, I went over to Ward 86, which had just been started. Half the floor was still under construction. And a friend of mine, who's still a friend but isn't in San Francisco any more, a nurse named Laurie Hauer, was working there. If I recall, I don't think she was working for Paul; I think she was working for Connie [Wofsy] through the infectious disease department as a research nurse on the grants on herpes, which I think are still going on, and that I think are now administered by Sharon Safrin.

So I walked over there, and I had met Paul and Connie when they came over to see patients. Paul Volberding was there in the morning, and Laurie said to him, "Do you know that Gary's a nurse practitioner?" And Paul said, "I've been thinking about hiring a nurse practitioner." [laughter] Then in the fall of '83, I interviewed with Gayling [Gee], with Paul, with Connie, and with Donald [Abrams], and the next thing I knew, I was there. J. B. [Molaghan] started right around the same time.

I think I was told at some point that when Paul had said to the gay community, "What can we do?", they said, "Hire gay staff." So I always felt like J. B. and I got those jobs because we were gay men.

¹ For more on Feldman, see the oral history with Michael Helquist in this series.

Hughes: The reverse of what often happens.

Carr: Right.

Hughes: The way you tell this, it wasn't so much the disease that attracted you, or the patients; it was more circumstance.

Carr: It was a combination of all of them. In the seventies, with my experience with the St. Mark's Clinic, I became a nurse practitioner with the express purpose of working as a nurse practitioner in the gay male community. I came to San Francisco because that's where the money was, that's where the concentration of the gay community and the resources, et cetera, were, for the possibilities of doing that kind of work. Being in the hospital at the time AIDS was beginning was then a coincidence that was a product of those earlier circumstances. So I always think of my purposefulness about it and the coincidence of where I was as being intermeshed.

I'm sure if I had gone back to New York in the fall of '82 that I would have gotten involved pretty quickly in whatever response was being mounted to the disease in New York. I'm sure I would have, because from my experience at the clinic in the seventies, I knew the people who were doing it.

Hughes: The fact that this disease was happening in gay men made a difference.

Carr: Yes, that's true. If AIDS had happened to some other subclass of people, I don't know if I would have been drawn to it. You're absolutely right.

Hughes: In September 1982, the AIDS Clinic was not yet located in Building 80, right?

Carr: I believe that Paul came down to San Francisco General in the fall of '81 to start an oncology clinic, and he hired Gayling at about that time. The two of them ran the clinic alone for a year or so, or a year to a year and a half, in an inpatient unit that was not open as an inpatient unit. I believe it was 5B, which later became the original inpatient AIDS unit.

Hughes: Yes, you're absolutely right.

Carr: I think Paul and Connie got involved with each other as they began to see that the Pneumocystis and the KS [cases] were related. Donald [Abrams], I think, finished his fellowship in July '83 and came on with Paul and Connie right after that. So I think Donald had really only been there a short time when I started.

Hughes: Well, you mentioned the date September '82--

Carr: Was when I came to San Francisco. My start date at Ward 86 was December 5, 1983. In fact, my twelve-year anniversary date was just last week.

Hughes: The clinic opened in January 1983. So it had been going almost a year by the time you arrived.

Carr: Yes.

Physical Layout

Hughes: Well, tell me what it was like. What did you step into on that first day?

Carr: If I recall, we only had half the floor. When Gayling showed me around on my interview, I remember stepping over construction debris on the north side of Ward 86, and the clinic only had the south side. In it, there were the patient rooms; there was the back room--that's now the treatment room with the hospital beds--which had cubicle subdivisions in it. I think there were four cubicles: offices for Paul, Connie, and Donald, and a fourth for a receptionist-secretary. The room that's now the social work room was Gayling's office, and then in what's now exam rooms nine, ten, and eleven was Andrew Moss's epidemiology group; they had those three rooms as their offices. They later moved to Ward 95, and I think they're still there.

The Epidemiology Group

Carr: Andrew and some of his people who worked with him, mostly Dennis Osmond, were very important people in those early days.

Hughes: Why do you say that?

Carr: They were really part of the discussion and the discovery and the decisions about what we were going to do. I remember Andrew was already doing his epidemiology studies. Quite some time before the virus was discovered, I remember Connie telling me, "Whatever this is, this is a virus." And then there was Donald's work with lymphadenopathy and the development of the concept of ARC [AIDS-

Related Complex] that clearly showed that this syndrome covered more than just the people who had the acute diseases.

I remember the discussion about looking at people's laboratory panels before HIV was identified, before there was any concept of a causative agent, and noticing what abnormalities were consistent in our patients that could help us know whether or not they had "it." You know, "it". I remember Connie telling us that whatever it was, it was clearly a virus.

Andrew, I think, was the person who originally told us that it was transmitted the same way as hepatitis B. And that was very important, because we were all struggling with, were we going to get it as gay men working there? Which of us maybe had it already? Were we going to get it from the patients?

Molly Cooke

Carr: Did you interview Molly Cooke?

Hughes: No, I didn't.

Carr: She's Paul Volberding's wife.

Hughes: Yes.

Carr: Back in those days, that wasn't so well known. I remember one nursing conference in the hospital when I think their second son, Alex, had been born. Gayling said from the podium as she was introducing Paul to speak, "I want to congratulate Dr. Cooke and Dr. Volberding on the birth of their son." There was dead silence, because everybody knew who both of them were, and a lot of people didn't know they were married. [laughter]

But anyway, I've heard Molly speak on videotape or television, really interestingly, about what it was like to be pregnant in those days--when Paul was working with those patients, is the point. Right now, I'm trying to think about it. You know, I can remember these things, but it feels so old. I was so clear that I wanted to work with these patients. I think I must have been pretty brave. But I didn't feel brave.

Hughes: At the time you didn't feel brave?

Carr: I just felt clear that, as a nurse practitioner in the gay community and caring about the health of gay men, that this was clearly something I had to do.

Hughes: Even if you were risking your own health.

Carr: Yes. The things that Connie and Andrew said early on were reassuring: there was something we could do.

Do you know who Misha Cohen is?

Hughes: No.

Carr: She's an acupuncturist in San Francisco, and although her name belies it, she's quite a specialist in Chinese medicine. I used to go to her for acupuncture in those days, and she used to do treatments on me to enhance my immune system. Some of my lesbian friends gave money toward my going to her, because they were afraid I was going to get sick if I weren't there.

Fear and Horror

Hughes: You were reassured that this "something," whatever it was, seemed to be transmitted like hepatitis B, because that meant that there were precautions that one could take? Or was it more that a known entity was less fearsome than a mystery?

Carr: I have no memories of being afraid or being brave. I just wasn't afraid. I just said to myself, This is what I want to do. This is important. The community needs this, and it's what I want to do. I remember there were people who stopped speaking to me. My mother for years didn't tell anybody what I did. My relatives for years thought I still worked in the trauma unit.

Hughes: What about other people that you were working with? Did you sense that they were fearful?

Carr: Yes. When I first came to San Francisco, I was in a gay men's support group, and there were two professional therapists. One of the therapists was really strong: "You don't want to do that; you're wrong." I dropped out of the group because he was so opposed, because I felt like he was so nonsupportive.

Hughes: He was worried about your health?

Carr: I don't know what he was worried about. I think he was coming from his own fear.

There was one guy whom I dated for a while--
##

Carr: --in the early days when I first moved to San Francisco whom I met through friends. In fact, an old friend I knew from New York who was living in Berkeley made me a match with him. And in breaking up with him, I found out that dating me was his way of dealing with his approach/avoidance fears about the HIV epidemic.
[laughter]

Hughes: Oh, my heavens.

Carr: I'm using mixed terminology: I should say dealing with "it." It wasn't called the HIV epidemic then.

Hughes: Yes. Although it had the name AIDS by then.

Carr: Yes, it did. The name AIDS existed when I started working at Ward 4D.

During the year I worked in the trauma unit [December 1982-August 1983], there was a gay community meeting or presentation in that junior high school right across from Dolores Park, at 18th between Dolores and Church. I think it's called Mission High School. It was the first time I ever saw Paul and Donald and Marcus Conant. They and Bobbi Campbell explained about the new disease that was affecting gay men. I don't remember what they said. I remember they showed a slide of the bottom of Bobbi's feet with KS lesions.

Hughes: Was the presentation directed towards KS, as opposed to PCP?

Carr: I don't remember. But I remember a lot of discussion of KS, and, I guess, the earliest version of safe sex.

Hughes: When was this?

Carr: This would have been probably in early 1983. I just went as a regular person in the audience. I think I went alone. I got sick. I thought I had the flu by the end of the meeting. But clearly, what I had was a vaso-vagal reaction, because I was so horrified. But I was sick; I couldn't drive home; I had to call a friend to come get me. I went home and got in bed and stayed in bed the whole next day, thinking I was sick. Then I realized afterwards that it was just my horror, my reaction to what was happening.

Hughes: Why did that particular occasion come across so strongly?

Carr: I think it might have been the first time I'd heard of the epidemic--no, it couldn't possibly have been. I had only been back from Israel a short time. I don't remember hearing about it in the brief time I was in New York before I came out West. I have this old college friend named Suzi who lives in the Bay Area. She was a nurse at SFGH for a long time, and in fact I actually stayed with her when I first came to San Francisco in '82 and started working at General. Part of the way I got work at General was her telling me who to call.

She was friends with Bobbi Campbell. Had they gone to nursing school together? She took me to meet him. She wanted me to meet him as a way of me learning about the disease. He already had KS at that time, and when we met, he gave me a big, wet kiss on the mouth, which was a very political thing that he was doing with people, to see how scared they would be. I don't remember it scaring me; I sort of liked him. God, he's dead over ten years; it's unbelievable.

Safe Sex Instruction

Carr: But it was from meeting Bobbi that day that I learned about the epidemic. I remember him specifically telling me things, like you would tell a new gay man in town. I don't remember exactly what he said, but I can remember being there with him.

Hughes: His advice was along the lines of, This is what you need to do to protect yourself?

Carr: Yes, safe sex, whatever state it was in in those days, I don't even know.

Hughes: He did a lot of community education.

Carr: Yes. He used to call himself the AIDS poster boy. So I met him early on. I went to that meeting with Paul, Donald, and Conant early on.

Hughes: All of which were names that you'd never even heard before?

Creating an Integrated Clinic

- Carr: That was the first time I became aware of Paul and Donald's existence, I'm quite sure. And then when I started working on 4D, I don't remember Donald, but I remember Paul and Connie coming over to see the PCP patients. I got to meet them and chat with them, so much so that by the time I came to my job interviews with them, they had a clear sense of who I was.
- Hughes: The fact that Paul came implies that he was linking PCP with the KS that he was seeing in his own clinic.
- Carr: Oh, yes. I would say that clearly was happening before I was at the clinic.
- Hughes: And what about the other opportunistic infections?
- Carr: You know, I don't remember other opportunistic infections then. I really have this memory of a time when it was KS and PCP. And then the third thing was PGL or progressive generalized lymphadenopathy, the concept that Donald came up with for the people who had a lot of lymph nodes. In fact, when I came to the clinic, Donald was doing that original study where he was following 200 people, and I was seeing them with him.
- Hughes: Well, I would like to know about ARC [AIDS-Related Complex].
- Carr: That's sort of what I'm talking about.
- Hughes: In September, 1982, the CDC published the official definition of AIDS.¹
- Carr: Right, the list of diagnoses. Donald took off from there and recognized the subclinical stuff.
- Hughes: Well, talk about what ARC was conceived of, and how you related it to the definition.
- Carr: Well, you know, in the early days, Monday morning was Paul's KS Clinic; Tuesday morning was Donald's lymphadenopathy clinic, and Thursday afternoon was Connie's PCP clinic. Wednesday was oncology. And what did we do Friday morning? I think very soon afterwards, we added another KS Clinic on Friday morning. That,

¹ CDC. Update on acquired immune deficiency syndrome (AIDS)--United States. Morbidity and Mortality Weekly Report 1982, 31, no. 37:507-514. Hereafter, MMWR.

of course, didn't last long, and it was a conscious decision--I think mostly under Paul's leadership, but I'm sure with all of their input--to go to the concept of AIDS, and have providers and patients stay together for the course of illness, not based on what diseases they got, although it sort of started out that way--who had PCP, who has KS, who had lymphadenopathy.

Hughes: You're meaning that Paul proposed an integrated approach?

Carr: Yes.

Opportunistic Infections

Hughes: Well, it would seem to be a good idea from a patient care standpoint to have an integrated approach, but also wasn't that what the disease demanded? It had become apparent that KS patients had PCP and vice versa?

Carr: Oh, yes, that decision was clearly driven from what happened, yes, no question. I don't remember exactly when we stopped saying PCP or infectious disease clinic. But it feels to me now, as much as I can remember, like all the other opportunistic infections other than PCP did come later.

Hughes: Is there a biological reason why that should be?

Carr: From what I know about the epidemiology of the Pneumocystis organism, I think the percentage of the population that's exposed to it, just from soil and dust, is very, very high, and probably higher than all of the other organisms that can be early-stage organisms, like Toxoplasma and Cryptococcus. The other organisms that are probably as ubiquitous as the Pneumocystis organism--Mycobacterium avium, which is also called MAC, and cytomegalovirus, which is also called CMV, we now call later-stage diseases. I think we didn't see them until later on, until people started living longer after having Pneumocystis.

Sometimes when I teach the nursing students, I say, "The reason there's more cancer in the twentieth century is the fact that we can treat tuberculosis." In other words, people survive one cycle of disease in their life to reach the next. So I think that's why MAC and CMV came later.

Although there was MAC early on, because in the early days, Connie was the PI, principal investigator, for a drug called ansamycin, which is the same drug that's now rifabutin in common

use for MAC treatment and prophylaxis. But in the early days, she was the PI, and before we had research nurses, myself, J. B. Molaghan, and Tracy Moran--the other nurse who's been in the AIDS Clinic for a long time--each in addition to our regular nursing jobs took studies and were research nurses as well. I was the ansamycin research nurse, so everybody who wanted ansamycin through Connie contacted me. So that was actually my first clinical research experience, but it's my reminder that MAC was actually there pretty early on, although not much of it.

Hughes: Within your first year there?

Carr: Probably shortly after my first year, probably by '84. I don't exactly remember. If you go back to Connie, she'll probably know the dates better than I do. I have papers I could probably shuffle through in dusty boxes under my desk in the hospital. Well, '84 was really my first year, because I started late in '83, so maybe early '85 was the beginning of the MAC.

Lymphadenopathy and AIDS-Related Complex

Hughes: Donald Abrams, and I suspect others, hoped that patients with ARC would not progress to AIDS.

Carr: I wouldn't say that about ARC. I would say that about the lymphadenopathy syndrome, which I think predates ARC. When Donald was doing the original study, following the 200 people with lymphadenopathy, I think his hypothesis, if not his wishful thinking, was that the lymph nodes would represent a successful attempt by the body's immune system to fight off the virus, and that the diffuse lymphadenopathy would be an end-stage event and people would go on to have a normal life course.

That didn't turn out to be the case. I don't know exactly when, but there was a point where all of the 200 original people had clearly gotten sick and died. I always remember one that was lost to follow-up was found again when we saw his name on a square on the AIDS Quilt.

Hughes: [tape interruption] Gary, you mentioned that lymphadenopathy really preceded the concept of ARC.

Carr: My memory is that lymphadenopathy was the concept where Donald had the hope that it was the terminal event of exposure to "the virus," again before HIV was known. But I think that by the time the term ARC was used, it was already recognized to be a part of a

natural history with a very bad prognosis. I can't remember any particular point where it became accepted that there was a universally terminal prognosis. I think all along the acceptance of that has been resisted. I'd say that most people in the clinic, like myself now, would say that they acknowledge that, but I think there are still a lot of places in the community where people don't. So even now, I would not say that it's generally accepted in all quarters, although it is in some, that there's a universally terminal prognosis.

But separating that as an issue, I'd say that lymphadenopathy syndrome and ARC in my memory go on different sides of that issue. I think that by the time the concept of ARC came in, it was recognized to be part of a natural history and not thought to be a terminal event. Have you interviewed Donald?

Hughes: Yes.¹

Carr: Yes. So he would be the person to check back for the exact answer to this question, but that's my memory.

Hughes: Now, by terminal event, you mean--

Carr: I mean HIV infection being recognized to be almost universally fatal to the infected individuals. No, by terminal event in lymphadenopathy, I mean the end point of the exposure. Terminal event in lymphadenopathy is not the same usage as terminal disease. I'm sorry. One of the main things I've learned as a doctoral student and being exposed to all this medicine is that you have to be specific with terminology. [laughter]

AIDS Definitions

Hughes: The collection of conditions that make up ARC stands conceptually apart from the CDC definition, is that not true?

Carr: Yes, that's true. I happen to know a lot about this, because I teach it to the nursing students every year. It is true that the 1982 original CDC definition of AIDS was a list of diseases that were all tissue-pathology-diagnosable diseases, things that you

¹ See the oral history with Donald I. Abrams, M.D., in The San Francisco Bay Area AIDS Oral History Series: The Biomedical Response, 1981-1984, Volume III. Regional Oral History Office, University of California, Berkeley, 1996.

could either see under the microscope or culture. Everything, if I recall correctly, and I'm pretty sure I'm right, on the 1982 list was tissue-diagnosable disease.

The 1985 revision,¹ which included the HIV antibody test, the list of things that were ruled in and ruled out by it, were, number one, the more peripheral, questionable cases only, because it was so clear by 1985 that if somebody got Pneumocystis pneumonia, you didn't need to HIV test them just because it was available. I'd say for many, many years after that, and maybe even to this day, probably a lot of people who get Pneumocystis pneumonia and have AIDS and have the full course of an AIDS disease may never get HIV tested. It's just clear.

But in 1985, the case definition using the HIV antibody test really ruled out the more borderline cases, the cases that were questionable. But the cases on the list, what could be ruled in or ruled out with the HIV antibody test, were still all tissue-diagnosable diseases. It wasn't until the '87 revision,² which had wasting syndrome and dementia, that you had syndromes as part of an AIDS case definition. And it wasn't until January '93 when the definition became HIV infection evidence or a positive antibody test, plus a CD-4 count of under 200, regardless of the clinical condition, that it really became an epidemiological definition.³

Some people have told me that that changing of the definition to the T-cell count below 200 was resisted for a while and took place between presidential administrations. Leading up to the '92 election, the Bush administration didn't want to have that statistic that would inevitably happen of the numbers of cases suddenly jumping up. I don't know whether that's true, but I've heard people say that.

Hughes: Why do you place T-cell counts under the rubric of an epidemiological definition?

¹ Revision of case definition of acquired immunodeficiency syndrome for national reporting--United States. Journal of the American Medical Association 1985, 254:599-600.

² CDC. Revision of the CDC surveillance case definition for acquired immunodeficiency syndrome. MMWR 1987, 36, no. S-1.

³ 1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. Journal of the American Medical Association 1993, 269, 4:460.

Carr: Oh, because it's based on the natural history of HIV infection, rather than based on what opportunistic diseases people get.

Hughes: So you're saying that very first definition, the 1982 definition, was not epidemiologically based?

Carr: No, of course it was, in the sense that epidemiologists were the ones who were surveying what diseases people got and what "risk groups," quote unquote--another term that's falling by the wayside--they were parts of. So yes, it's very much so. But what they call the case definition of AIDS was based on the tissue-diagnosable opportunistic infections. So it really was only capturing a late stage of disease, and to the extent that, for reasons nobody really understands, there are some people who go a very long time without getting opportunistic infection, it wasn't capturing everybody.

ARC was brought in to capture those people who clearly had "it", but not the diseases on the list. Because again, even before HIV discovery, the lymphadenopathy, thrush, and hairy leukoplakia, which was discovered by Deborah Greenspan--now, I can't remember whether hairy leukoplakia was identified before the existence of the antibody test, but I sort of think it was.

Hughes: So relatively early on, you and the people that you were working with, and I suspect groups elsewhere--New York, for example, probably also Los Angeles--were finding that the CDC official definition--

Carr: Clearly did not cover everybody who needed to be covered, in terms of the appropriateness of receiving care in that clinic, in terms of social service benefits--Medicaid, Medi-Cal, disability benefits, et cetera--and recognition in the community of what was going on and what kind of problems people were having.

Hughes: It would seem that the problem particularly applied to what you were trying to do in the screening clinic, which was to differentiate between patients who indeed had AIDS and those who did not.

Carr: Ultimately, before the HIV antibody test, there was no way to do that, and we never completely sent anybody away. But there were ways to tell when people appeared to be at risk of progression. For instance, we identified a lot of people who had ARC by the "minor" signs and symptoms--the thrush, the hairy leukoplakia, the lymph nodes--I can't remember exactly--facial seborrhea, all these things you see in people with AIDS that are so characteristic and that you just don't see that much in young men who don't have immune problems.

Hughes: The AIDS definition you were using in a clinic situation was a pace ahead of what the CDC had come up with?

Carr: That's true; we weren't always following the CDC. I'm quite sure we used ARC before they did. I'm quite sure that our criteria for who was appropriate or who had the right, or however you would want to call it, to come to the clinic was much broader and much more based on serving the needs of the community.

Hughes: Did the community also develop a more flexible concept of what this disease was? I mean, you could have whatever it was without having KS or PCP?

Carr: Yes.

Hughes: Or even some of the opportunistic infections.

Carr: Yes. There's always been a little bit of a problem around that. There's been a whole secondary gains issue in the gay community for being infected. There have been people who wanted to convince us they had it so they could get benefits and housing and money that was available to people with AIDS, and that still continues to now.

But yes, I think that our criteria for including people in the definition, and for servicing people when they were disabled, and for providing support for people, providing care for people was loose and community-based and flexible. The leadership came a lot from Donald, but from Paul and Connie too.

Markers of Suspicion

Carr: I was very much involved in developing a set of laboratory parameters. I used the concept, "markers of suspicion". Even before HIV antibody testing and T cells testing, there were certain things we'd see consistently in the most routine hospital lab tests.

Hughes: Such as?

Carr: A low white blood cell count, a high count of the protein globulin, nonspecific elevations in the sedimentation rate, nonspecific elevations in an enzyme called LDH [lactic dehydrogenase], all these kind of things that you'd just see again and again and again. So you could see it on the most basic hospital laboratory screening profile available anywhere in the

developed world in this way that's completely routine and consistent. J. B. and I remember discussing how we could tell who had it.

Hughes: Just on that basis?

Carr: Yes, absolutely. And all these years later, I still look at those things.

Hughes: When the antibody test came along, these people would test positive?

Carr: I can't say it's 100 percent, but boy, it's really up there. And ultimately, you can't say it, because there are so many different things that can affect all these laboratory tests. Because we couldn't make a diagnosis on the basis of laboratory tests, we used the concept "markers of suspicion" on the physical exam and the laboratory diagnosis. I still use this concept in slides I show to nursing students and visiting nurse practitioners who are here to learn about AIDS.

Hughes: And what do you counsel them to do with markers of suspicion?

Carr: These are the people you want to counsel about safe sex; these are the people you want to watch. Not in an AIDS clinic, but in a general practice, sometimes people have problems that you may suspect are due to immune deficiency. And if people don't suspect themselves as being at risk for AIDS, these markers can be helpful in whether you want to counsel that person to get HIV tested. They could have a sexual partner who's fooling around on them, or using drugs or something that they don't know about--a lot of different situations.

Hughes: So these markers of suspicion don't necessarily mean progression to AIDS?

Carr: No, they're more markers of suspicion that somebody has HIV. That's not terminology we would have used back in the screening clinic days, but there were just certain things that were so consistent.

Hughes: So from what you're saying, you used much more than the CDC definition in diagnosing AIDS.

Carr: The CDC definition wasn't inclusive enough. It didn't tell you who was at risk; it didn't tell you who you had to counsel about safe sex; it didn't tell you who you might want to see again in a few months just to make sure they were all right and just to make sure they weren't getting any of the symptoms.

The AIDS Test

Carr: Then if you remember also, in the early days of the availability of the test, it was not something that everybody just started doing. There was a long period where a lot of people resisted getting tested. There was the fear of discrimination; there was the fear of losing health insurance; there was the fear of these crazy right-wing ballot initiatives being used to discriminate against people. It wasn't something that everybody just went out and wanted to do. So it was still useful at that point to have a sense of which side of the fence you would fall on in terms of whether you would counsel people to get tested. And it wasn't always the more suspicious you were, the more you'd tell them to get tested. Sometimes, the more suspicious you were, the more people would be afraid to be tested. So the markers of suspicion were used for a lot of different things. Yes, people were really afraid.

A lot of our blood--mine, I think Donald's blood, maybe even Paul's--went to [Robert] Gallo's lab to serve as the healthy controls. Supposedly we were the healthy controls, but they also really wanted to answer the question, Are we going to get it from the patients? I always remember one day--I was at the end of the hall in the clinic, on the north end at the nurses' desk, and Donald got off the elevator and he said [shouting], "Gary, you're negative." I later said to him, "Donald, if I weren't negative, would you have shouted it down the hall?" He said, "That's a good question." [laughter]

Hughes: Do you remember being anxious?

Carr: I don't remember.

Hughes: Because Donald said he was.¹

Carr: Yes, I know he was. He talked about it later.

Hughes: Were there indeed patients who ultimately died who never developed the classical conditions of AIDS?

Carr: Oh, absolutely, yes. That happens a lot. There are a lot of people who waste and die without ever having any of the major opportunistic infections. Ultimately, nobody knows that they had

¹ See the oral history with Donald I. Abrams, M.D., in the AIDS physicians series.

AIDS. I think that tends to happen now more that we're using prophylaxis, but it happened in the early days too.

Hughes: Would you think of those patients as AIDS patients?

Carr: Yes, absolutely. In the earliest days, yes. Although if I recall correctly, I think we used to talk about people who died with ARC. Yes, we definitely did; I remember using that phrase exactly that way. We would talk about people who died with ARC, and they're the patients we're talking about now, and that's the terminology we used for them in those days.

Hughes: What was the process for getting a new condition admitted, if that's the word, to the official CDC AIDS definition?

Carr: Again, you have to talk to the docs about that.

Idiopathic Thrombocytopenia Purpura

Hughes: Well, in the chapter that you wrote in Tracy Moran and Gayling Gee's book¹--or one of the chapters that you wrote, because you wrote three--you mentioned a condition that I haven't heard people talk very much about, and that is ITP, idiopathic thrombocytopenia purpura, quite a mouthful.

Carr: Idiopathic means without a known cause; thrombocytopenia is a low platelet count, the disappearance of platelets, the cell fragments. You know, in the bone marrow, the body manufactures the cell called the megakaryocyte, and it sort of fractures and becomes the platelets, which are cell fragments that circulate in the body. You know this, right?

Hughes: Yes.

Carr: They're one of the elements, along with prothrombin and other things, that cause coagulation or clots. We would find people who had severe thrombocytopenia, and for a long time, it was considered part of the definition of ARC. Purpura means bruising on the skin, and a lot of these people would have that. Thrombocytopenia purpura previously had been a largely female disease, so we felt we were seeing a different epidemiology.

¹ Gayling Gee and Tracy Moran, eds. AIDS: Concepts in Nursing Practice, A Guide for Nurses and Nurse Practitioners. Baltimore: Williams and Wilkins, 1988.

There are two parts of the immune system: the cell-mediated, which becomes deficient in AIDS, causes the other part, the antibody part, to make extra antibodies. Some of those antibodies may, just by coincidence in some people, be anti-platelet antibodies and destroy platelets. So in these patients, when you do bone marrow biopsies, the production of the platelet-producing cells is normal, but the platelets sort of disappear. So it's an autoimmune disease.

We were starting to see it in people who were at risk for AIDS, and so it became part of ARC. It's not a late-stage disease; it's something you frequently see in early stages of diseases, with T-cell counts just a little bit below normal.

Hughes: But it is AIDS-related?

Carr: Absolutely, because it occurs in people exposed to HIV who are cell-mediated-immune-system deficient.

AIDS-Related Conditions Outside the CDC Definition of AIDS

Hughes: Would you say that there were four conditions early on that didn't fit into the classic CDC definition?

Carr: So you're saying lymphadenopathy, thrush, hairy leukoplakia, and ITP?

Hughes: Well, I guess then there are five, because what about the neurologic symptoms?

Carr: I don't remember seeing that many neurologic symptoms in the early days. [tape interruption] The ITP patients also used to come to Donald's lymphadenopathy clinic, which evolved into Donald's ARC clinic. And it was really good, because a big part of his training was as a hematologist.

In those early years, Tuesday morning was Donald and me seeing those patients, just the two of us, and him constantly teaching me. Not formally. Tracy Moran was the nurse, and it was just the three of us, for years and years. J. B. was part-time at first, so I don't think he was there on Tuesdays.

[looking through book] Yes, wow, dementia, myelopathy, and peripheral neuropathy. I didn't realize I had been talking about those that early on. That's interesting.

Hughes: Well, that book was published in 1988, which probably means you were seeing it at least as early as 1987.

Carr: Yes.

AIDS-Related Dementia

Carr: I always feel that the first case of dementia I ever saw was a man named Michael Flowers, and I can't tell you the year. I think it was probably about '85 or '86-ish. He was a very young man who had been a street prostitute on Polk Street. When he got sick, one of the hotel owners where he used to stay for a while took pity on him and took him in and gave him a free hotel room for the last few months of his life. The hotel owner would bring him in for medical appointments. I even went to visit him at the hotel a couple of times.

He would sit in the hotel at the window, I think it was a rocking chair, and he would just sit and stare out the window for the longest periods of time. I would see him be perfectly content to just sit there and stare for hours. I remember talking about it with people and thinking, Is this a Buddhist Nirvana? What is this? And now I think he was probably the first person I saw who really had AIDS dementia.

I was the blinded clinical monitor in the first AZT trial--this was in '86--but the point is, there's always been a discussion about AZT reversing dementia. There was one guy, he'd been a real corporate type of guy, who would come in in a suit and fancy tie--people dressed that way in Ward 86 still to this day seem out of place--but he was in the first AZT trial. We were giving pretty high doses, higher than what we give now. I always felt he was a little demented already when he started that trial, and that his dementia reversed on AZT. I remember that as another early case.

But Michael Flowers was the first case of dementia that I really was aware of in a clear way. And he probably had very late-stage dementia to just sit like that, but who knew? Michael was definitely before this chapter was written.

Hughes: Now, why would dementia be observed later in the epidemic?

Carr: It's something that doesn't happen until people live longer. It took a while to reach that point, where people were living long enough after early opportunistic infections. And the other thing

I think is because it's subtle, and it's not so specific. It's something that can really creep up on you. It can be very hard to spot.

Sometimes the more you know patients, the harder it is to find. Sometimes if you know patients well, you don't see those subtle changes. Sometimes, if they meet another health care worker, like the social worker or the desk clerk might say, "Don't you think he's a little demented?" And you'd realize, "Yeah, of course." When you know him and care about him, it just takes a while sometimes.

The Nurse Practitioner

Hughes: Well, I think what we need is a definition of a nurse practitioner, and what a nurse practitioner does that an R.N. doesn't do, and what your relationship is to the medical supervisor. There is inevitably a hierarchy, is there not?

Carr: Yes. Nurse practitioners are registered nurses with advanced training, usually on the level of having a master's degree in nursing, in medical primary care. We learn how to do a medical history, medical physical examination, laboratory evaluation, interpretation of laboratory results. Nurse practitioner programs were started in the early sixties to provide health care in medically underserved areas. They were originally organized to go to the most rural parts of the country, because those were the most medically underserved.

Today, to the extent that the rights and responsibilities of nurse practitioners vary from state to state, some of the most rural states have the most progressive legislation in allowing nurse practitioners independence in practice. The most noticeable was the Frontier Nursing Service in Kentucky, where nurses were already practicing on this level for quite some time. Very medically underserved; the nurses were basically doing all the health care. So in some cases, the beginning of the nurse practitioner movement and state legislation, state by state allowing its existence, legitimized things that were already happening.

I've had contact with nurses in other parts of the world. There are no other countries besides the U.S. now that have a formal nurse practitioner situation. But a lot of times rural and medically underserved countries, like Africa, are the places where nurses are functioning on the most advanced level and the most

like nurse practitioners, just because they fill in the gaps where there are no physicians.

The evolution of the nurse practitioner role over time, I would say, has been that in the most rural areas of the country, nurse practitioners have continued to be generalists providing primary health care for communities in terms of the original concept. In the urban centers, such as the Bay Area, the same thing has happened to nurse practitioners as happened to medicine, in that we've become more and more specialized by body system or disease. For instance, I am now really, although there's no official designation of this, an HIV-AIDS nurse practitioner. I have forgotten so many other things that don't have to do with that. Although AIDS is an interesting specialty, because you see an enormous amount of internal medicine.

Hughes: Now, you are an HIV nurse practitioner simply through experience?

Carr: Yes. There's no academic or professional certification in that field. In terms of nursing academics, I'm what's called a family nurse practitioner, and that simply means that in the program I went to, there were components in the training to take care of people of all ages. Some people may be adult nurse practitioners. They went to a nurse practitioner program that specialized in the care of adults and didn't have a pediatric component.

Hughes: Well, my understanding of the history of the AIDS Clinic is that at first there were no nurse practitioners.

Carr: That's true. Gayling and Tracy did the screening clinic before there were any nurse practitioners. And what we basically added was the physical exam. I think that Gayling and Tracy did order laboratory studies, but that's different in a sense, too, because any nurse can order laboratory studies, but nurse practitioners are specifically trained in the interpretation.

Hughes: Was there ever any hint of resistance from the physicians themselves to having nurse practitioners take on some of their responsibilities?

Carr: From the clinic physicians, Paul, Connie, and Donald, and from the other physicians who were in the Ward 86 clinic in those early days, like Gifford Leoung and Tim Mess, no. Throughout the hospital system, there has always been some. We joke about how every year the new residents sort of get crazy when they hear they have to take admission reports or primary care consults from nurses. Then after they do it a few times, they mellow out, and by the end of the year, we're all friends.

Nationally, there has been a lot of pressure from medicine to try to squelch nurse practitioners. I'd say that since most physicians are in private practice, that has for the most part been economic, from physicians who are afraid nurse practitioners will undercut the business end of medicine. In the nonprofit sector and in academics in medicine, where they're not paid on a per-patient profit basis, I'd say there has been much less resistance.

Hughes: Because they look upon you as an assistant, taking some of the burden off their shoulders?

Carr: Right, especially in the UCSF system, where there is a lot of pressure on the faculty to produce in terms of research, lecturing, and publication. I think we do them a lot of service by sort of minding the store, because they're responsible for seeing patients and running a clinic and those things. To have us in the clinic and be able to trust us the way they do, I think really helps them a lot. And that's fine, because I'm not interested so much in an academic career in medicine. I'm interested in an academic career in nursing, but not in medicine, So there's no conflict; there's no competition.

Early Experiences in the AIDS Clinic

Hughes: There was a remark in Pogash's book which went something to the effect that when you first came to the AIDS Clinic, you followed Paul and Donald around.¹ Was that at your initiative?

Carr: I think I specifically told Carol Pogash my memories of my first day in the clinic, which was a morning when I went in with Paul when he saw patients and just observed and did nothing else. And I was completely, Oh, my God! I was overwhelmed. But I began picking up the ball and seeing patients on my own very quickly. But I do remember that first--I think I told Carol Pogash my memories of my first day, was what it was.

¹ Carol Pogash. As Real as It Gets: The Life of a Hospital at the Center of the AIDS Epidemic. N.Y.: Birch Lane Press, 1992, p. 162.

AIDS Clinic Physicians

Hughes: You were overwhelmed because there was so much to know, you mean?

Carr: Because it was so much to know, because it was intimidating to be around these people who were so bright and so involved and so special.

Hughes: Now, you're talking about the physicians?

Carr: Yes.

Hughes: All along, you'd been in touch with physicians wherever you'd worked, right?

Carr: Yes.

Hughes: What was different about these?

Carr: Oh, even in those early days, they had this angelic aura about them. It sounds like such a tacky, silly thing to say, but it's true. [laughs] And I still feel this way about all of them. What can I say?

Hughes: Well, define angelic.

Carr: At a time when so many physicians were running away from it and denying its existence, they were taking it on. That's what it was.

Hughes: Why do you think they did?

Carr: I don't know. Paul has talked extensively, and I think written, about this, and he always takes this "Aw, shucks" pose about it. But he just was open and compassionate enough as a person to take on the KS patients who came to the clinic.

Learning to Care for Patients with AIDS

Hughes: You explained how you'd seen PCP in the trauma unit, but there must have been other things connected with this syndrome that you hadn't seen. I'm gathering that there was no formal training?

Carr: No, it was just sort of following them around. Then there was a period--and this is still what new people do--when you present

every patient you see to the person who's training you. I remember presenting patients to Donald. I remember working in the Tuesday morning lymphadenopathy clinic with Donald where, after I examined every patient, he would then go in and examine them. He was training me and making sure I knew what I was doing.

Hughes: And then he'd come back and discuss--

Carr: No, sometimes he would just go do it and wouldn't discuss. Probably he would only discuss if there was a problem. You know, I don't remember the details that much.

Hughes: Is this the usual way of learning a new disease?

Carr: This is still what we do with new people on the staff. Now when there's a new nurse practitioner, that's what I do. I go in and examine the people they examine afterwards. I have students from the UCSF nurse practitioner program, and I do the same thing. I talk to the patients beforehand and tell them it's a student, and tell them I'm also going to examine them, and do it.

Hughes: Training could be done through an inservice, but it's usually hands-on?

Carr: Yes, it's hands-on. We do a lot of inservices for a lot of people, but for new people actually starting on the staff, we throw them in. [tape interruption]

Hierarchy among AIDS Medical Providers

Hughes: My perception of AIDS activities at the General is that it is an enterprise much less hierarchical than is traditionally found in medicine.

Carr: I think that's true, but it's still hierarchical, and I think everybody would acknowledge that. I think in general at the hospital, nursing is in a relatively powerful position compared to most hospitals, and I think that's because in the public sector, patients are taken care of in the inpatient units by teams of doctors who are not necessarily the most experienced. There isn't that situation you have in the private sector where everybody has their, "my" doctor. That just doesn't exist, and so I think the nurse becomes more important as a therapeutic agent.

And, as I said before, the fact that the doctors aren't being paid on a per-patient basis makes them much looser about accepting

the other kinds of health care providers. But I would not say that it's nonhierarchical; it is. There are certain decisions to be made, and they're made by certain people. There's only a very, very limited extent to which it's done by group process. I think that in academic medicine, with the combination of service chiefs, faculty titles like professorships, et cetera, there's just as much an established hierarchy as anywhere in society, and I think that we have that. We have that just as much as any university.

Saying that, I'd say that we have the privilege of a lot of good people in those positions who deal with it well, and I think that it's more than not having hierarchy. From what I hear on the grapevine, I'd say that we have more personally open medical faculty members in our program than most other places. Also, I think that UCSF has a reputation for being a sort of liberal medical school. And a medical school--and this is important in terms of HIV--where gay people can be out, as students and as faculty, relatively speaking. [laughs] That's something that cuts in on the hierarchy, and sometimes community identification creates a bond between staff members that crosses the hierarchy a little bit.

I've been exposed to different medical programs where I've worked before as a staff nurse and I hear around the country that there are people in positions like Paul Volberding's who are like crazy bulls. And he's not like that at all. But he does have as much power within the program as those people, so I think the feeling is not as hierarchical. I don't feel like he's treading on me; I don't feel like, Oh, my god, I have to do what he says or else.

I mean, I feel like I have to do what he says--he runs the program; he sets the direction--but he's a person you can trust and feel good about the way he does that. He's not my direct supervisor. Gayling had a very strong position as the head nurse of the AIDS Clinic. There was no medical director. J. B. is now in Gayling's job, but he and I are equals; he's not my supervisor like Gayling was. Now the medical director, John Stansell, is my supervisor; before him after Gayling, it was Michael Clement.

Neither with Paul nor with either of them have I ever felt like I'm under the gun; I have to do this. There's always room to discuss things and talk about what's okay and not okay, and when I have needs, to be away on a certain date or whatever, they're recognized. So I think that it's decent human people working within the hierarchy, but it is a hierarchy.

Hughes: Is that coincidence--

Carr: That's a good question: is it coincidence, or is it this particular disease? I think it's this particular disease to the extent that people had to have an openness about themselves to get involved. Yes, I think that's true. But it hasn't been that way everywhere. Look, there's been Gallo.

Hughes: So when you started, Gayling was your supervisor?

Carr: Yes. As I said, there wasn't really a strong medical director position as there later evolved to be.

Hughes: What did Gayling do as your supervisor?

Carr: She didn't evaluate my clinical practice; the physicians did. But she was my boss in the administrative sense, in terms of attendance issues, moving stepwise up the ladder in the university categories for your job--those kinds of things.

Hughes: What are the routes by which a patient could arrive at the clinic in the early days?

Carr: In those early days, we were basically very close to being the only game in town for people who knew or thought that they had the disease, again talking about before T cells and antibody tests. I think our reputation traveled very quickly in the community, because Paul, Donald, and other people did a lot of speaking, like at the meeting I attended. There was a lot of talk about us; I think our pictures were in the gay newspaper. There was a lot of discussion about the clinic in the media in general.

So many people were without health insurance that even not knowing about us, the situation in San Francisco was such that if you didn't have health insurance and you needed care, you ended up at SFGH in some way or another. So that's part of why the institution started out so centrally.

The Role of the Gay Community

Carr: Something that I think is very important about the role of the hospital is the context of the gay community here. Harvey Milk had been elected San Francisco supervisor, and the gay political clubs were very important at that time in terms of the kind of pressure the gay community here could put on the local municipal government to get its needs met on a level of dealing with issues that came up in the county hospital. I think it's no coincidence that we [SFGH AIDS medicine] evolved in a county where that

context existed. In New York City and in L.A. County and in a whole lot of other places, it still has not reached the point where the county hospitals have been so involved in such an organized and committed way. Bellevue may see more AIDS patients than we do, but it doesn't do it liking it and welcoming it and opening its arms at all. [laughs] So I think the gay community here is a big part of the context.

I only moved out here [to the Sunset District of San Francisco] about two and a half years ago. For most of my time at Ward 86, I lived in the Castro [District]. There was a long period where there was very little differentiation between my life in the clinic and my life walking in the street in my neighborhood.

I've been involved in the gay parades for many years, and in fact I'm one of the main people involved with organizing the hospital's group. We march as employees in the gay parade every year, and I'm involved in organizing that. I went back East for the twenty-fifth anniversary gay parade in New York, and in New York and in Provincetown people came up to me in public places and said, "Aren't you from Ward 86?" It just had that presence in the community.

I think even in the early days, a lot of people were referring people with AIDS to us, we were getting coverage in the gay media, and I think there were just as many people who sought out the public sector and the county hospital for their care, even if they didn't specifically know about the clinic.

Hughes: What about the KS Clinic?

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Carr: I can't remember exactly when Harry Hollander took it over, but it was evolving into the Adult Immunodeficiencies Clinic.

Hughes: That was 1984.

Carr: Yes, Helen Schietinger had already gone to Shanti Project, because that's where she was when I first started working and got to know her. I still know her, by the way. I don't know what the circumstances were, but there was something problematic about why Conant left the university and the faculty and went as private as he did.

Hospital Reluctance to Be Known as AIDS Centers

Hughes: The first AIDS clinic in the city was at UCSF, namely, the KS Clinic. And yet, AIDS activities as we know them today developed at the General. So there was a shift.

Carr: Yes. My sense of that is two things. I think that number one, really a lot of the people didn't have any insurance, and so they were forced to General and couldn't go to UC. And number two, I think to this day, UCSF in its quiet way is not warm to taking care of people with AIDS. From what I hear on the grapevine, I think that Hollander and those nurse practitioners who work with him, Susan [Stringan] and Cecily [Cosby] who I know, have always had a little trouble staying there. They've had their scares that they were going to be pushed out of their space. I think that the Ambulatory Care Center has functioned more like a private-sector hospital, and what I mean by that is they don't want to scare away the other paying customers by having things [an AIDS service] that might make them nervous.

A good example is Ralph K. Davies Hospital. They see enormous numbers of AIDS patients. When you start interviewing community-based physicians involved in AIDS, you'll find that a lot of them admit to Ralph K. Davies, and a lot of them have their offices in the Ralph K. Davies office building, 45 Castro Street. You'll find an enormous cluster there, which has been there for many years. And yet, they've never put themselves out as an AIDS center the way we do. Why? Because they have all these other people who are paying, and they don't want to scare them away with something queer and scary.

So I think we were able to be public in a way that they weren't, and I think that to this day, the hold of HIV and AIDS in the UC Medical Center on Parnassus remains tenuous. That clinic is small; it does not do significant community outreach. The few islands of expertise have not necessarily been in primary health care. I'd say the big islands of HIV expertise have been Dr. [Jay A.] Levy, the virologist, and the other is the Drs. Greenspan, John and Deborah who are married to each other, in oral medicine. But in primary care, UC has never stood out.

So I think that that clinic evolved into the present clinic, which has been there since then. We used to joke about the name being the Adult Immunodeficiencies Clinic, that they didn't use the word AIDS.

Hughes: Yes, I've heard that said too.

Carr: It seemed like bullshit. So I never thought of that clinic as competition or serious or anything like that.

We had a gay member of the board of supervisors then; it was [Harry] Britt. The gay community was able to intervene and pressure the municipal government, because the community was well organized, and was able to pressure the General but not UC, because the General was supported by city and county funds. UCSF is very financially aloof from the community of San Francisco. Its financial situation is all state and federal. I think it's one of the largest federally granted universities in the country.

Economic Status in the Gay Community

Hughes: Let me go back to one of your comments, which was that the financial constraints of some AIDS patients forced them, in a sense, to go to the county hospital, SFGH. I perhaps wrongly think of those early patients as being--of course largely gay--but also members of a different demographic group than we now have.

Carr: You mean middle-class, bourgeois?

Hughes: Yes. [laughter] So why couldn't they pay for their medical care?

Carr: I did an ethnography study in the Tenderloin, and in my paper, that I hope is going to be published in a nursing journal soon, one of the points I made looking at the Tenderloin was that the AIDS epidemic is migrating to where all epidemics migrate: the most marginalized sectors in society. Gay men are one group in society who can remain incredibly middle-class and incredibly marginalized both at the same time.

In the early days of the Castro, very many gay men came from pretty affluent backgrounds. We learned from Castro society the style to make it look like we were affluent. [laughter] Some gay men who come into the clinic always look so dapper, with the jacket and the sweater and the little shoulder satchel bit, but it's always the same jacket and the same sweater and the same shirt. People learn that kind of style, how to look that way.

The point is that, although we were very bourgeois in terms of our values and to some extent our lifestyles, we were living very transient lives. This was very characteristic of gay men in the seventies: we were all living very transient lives. I used to come out here and visit in the seventies and stay for four months, and then go back. I used to go to Europe for months. And we were

all living that way, and it was so much fun. Being an R.N., I had high earning power, but I was living hand to mouth. I never put anything away. When I would leave to go to Europe, I'd quit my job, give up my apartment. I'd go back to New York; I'd stay with friends until I found a job and an apartment. Yes, we had this appearance and these values of being very bourgeois, but we were living very hand to mouth. And there were thousands and thousands of gay men doing this.

So although we were quite stylish, having something like health insurance was very low on our list. A lot of people were doing what I was doing. The economy was such that you could do it: coming and going from jobs. Leaving a job, going to live in L.A. for a few months, coming back, getting another job. And that doesn't leave you with health insurance.

Hughes: I see.

Carr: We were living such transient lives. I think it was a product of the whole sixties thing where everybody thought we'd be young forever and never die. What I say now is, "Sex was to gay men like Cadillacs were to my old uncles from Europe." It was like this self-esteem thing, when you didn't really have all that much. It was getting back for all the years that, as young people in the closet, you really didn't have very much fun, and you were making up for that time. It was a commodity that was being pushed on us, in a sense, to sell us things.

So yes, we were a clinic for a more bourgeois population, and for many years in the early days of Ward 86, it was a more middle-class clinic than the rest of that hospital. I don't like it when people talk about "the changing epidemic" or "the changing face of AIDS." I feel like it's a racist code word, like saying "bad neighborhoods." I hate it, and I think it's really inappropriate. But what I would say is that the clinic is migrating to be more like the rest of the hospital. So it isn't that the disease is becoming more marginalized as much that it happened in the one group that was able to be marginalized but had a lot of style.

Did you ever see those old Andy Warhol movies with Joe Dellasandro?

Hughes: Yes.

Carr: It was like that sense of a welfare queen on the Lower East Side of New York. That's what a lot of people I knew were into in the seventies. That's where the term piss-elegant comes from.
[laughter]

Hughes: Does your paper say--

Carr: No, it doesn't say any of that; it just talks about people's marginalization. I just make the point that the disease is really like other diseases, in terms of striking the most marginalized people, even though it didn't look that way at first. No, I don't go into any of what I've just said; I don't think I've ever written down any of what I just said. But I think a lot of people will agree with what I've just said.

Risk Groups

Hughes: Well, it makes me think of the risk groups, which you brought up in passing, and which I think you termed "passé."

Carr: I said it's another term that's falling out of use, yes. I'd say that whole risk-group notion belongs in the early days, when we didn't have the full picture of what we were looking at. It belongs along with that phrase I used, "markers of suspicion." And I think that it was useful then, when we were trying to figure out what was happening and didn't have real concrete parameters. I think that now it's very clear that this disease is associated with certain activities that anybody can do, and whether you do them or not doesn't have to do with your sexual orientation or social class. But I think that there are still social factors that drive people from certain sexual orientations and social classes to do them, and I see that as a function of economics and class.

Doctoral Candidate in Nursing, UCSF

[Interview 2: January 9, 1996] ##

Carr: I'm working on my Ph.D. in nursing in the School of Nursing at UCSF, and I've finished my coursework and I'm a candidate now. My study proposal is a grounded theory study, the methodology developed by Anselm Strauss. The question is the nature of the interpersonal relationships between health care providers and patients in the AIDS Clinic over a period of time, and whether they have therapeutic value for the patients and the providers.

It has several levels. It has a clinical patient care level, which is whether it has therapeutic value for the patients. It

has a health care worker professional level in terms of the whole controversy about health care workers who are afraid to work with AIDS because of the stigma. And those of us who do it find it so much more satisfying and elevated, simply because it's at the edge, than a lot of other jobs. I hope there will be a piece about what health care workers say to put out to other health care workers who are reluctant to get into AIDS work, but this is the very personal piece. The third thing is a narrative, qualitative piece, capturing the history.

Academic nursing is now staking out in its own direction, moving away from medicine and more into a health science-behavioral discipline.

Hughes: As a way to differentiate itself from medicine?

Carr: Well, I think as nursing gets more academic and has more people with graduate level degrees, it needs to establish an identity of its own. I see it moving in the direction of a health-care-related social science, rather than the strictly quantitative clinical science that medicine is.

Reflections on the Nursing Profession

Nursing and Medicine

Hughes: What are your thoughts on how the epidemic has impacted nursing?

Carr: I think nursing has always been the silent, subservient partner in health care. Nursing has a very rich, deep life and background of its own that's invisible in the hospital, because it's so overwhelmed by medicine and so subservient to medicine in a way that exactly reflects relationships in society between women and men, medicine being men and nursing being women.

When I was in my early twenties, I lived for a while with a family in Morocco. In the Middle East, what tends to happen is men and women have really separate societies. Part of it is a function of oppression, because of the way women are sequestered and hidden, but they have this whole society and life of their own that's very beautiful. The men see the women as demeaned servants who just do the housework, and the men just come in, expect to be fed, they eat, they leave. They don't see anything about women.

That's how I see the relationship of medicine and nursing. Nursing has a very rich culture which organizes the hospital, and medicine just walks in and expects everything to be a certain way.

Nursing as a Reflection of Society

Carr: I think nursing also reflects what's going on in society; nursing is striking out in its own direction and developing an identity of its own. I think the reason it's taking a little long, compared to the news that one hears about feminist movements, is because people who were comfortable with the most traditional kinds of sex roles went into nursing and medicine, because that's where the comfort of those roles was.

I think the combination of changes in society in the sixties and seventies made a lot of less conventional people go into nursing. There have always been a lot of gay people in nursing. This is a romanticized version, but people who do the history of gay people talk about primitive cultures. The gay people were the shamans, because they were unconventional. I think there's a little truth to that. I think marginalization has always made gay people concerned with community and caring.

Nursing and Gender Roles

Carr: So in nursing, like in the clergy, there's always been a lot of gay people. I think to some extent the cloisteredness of nursing also was attractive to gay people, because in a way it was an alternative to the pressure to get married [laughter] and a way you could be with a lot of people of your own gender.

When I first went into nursing in the early seventies, it was at a time when a lot of men were going into nursing. Actually, there were more men in nursing schools then than now, and there are more men nurses I think in my age and length of time in nursing group than there are among the kids coming in now. It was a period where sex roles were disrupted. And it wasn't only gay men. In my class in nursing school, there were ten men, and I think we were five gay and five heterosexual men. But there was camaraderie that was nice.

So nursing attracts a caring kind of people, and unconventionally sexually gendered people, and then along comes

this epidemic that affects gay people. And medicine, because it's about power and dominance, doesn't tend to attract gay people as much, although openly gay people in medicine certainly have been among the major heroes in this.

I do not ever mean to paint a picture of myself and other nurses in opposition to our colleagues who are physicians. I think one of the things that makes San Francisco General exciting, and I think would have been there without the epidemic, is the looseness and flow between medicine and nursing, which is nice.

Allen Berube's hypothesis in his book, Gay History, is that World War II really mixed up the population and led to a lot of sexually unconventional people traveling around the country as soldiers, who ended up staying in the big port cities. So I think the context of that community, the history of Harvey Milk, and the gay community feeling somewhat more enfranchised here than in a lot of places, and the kind of people who were going into nursing all came together when this epidemic started.

Nurses rushed in to fill a void. Nurses were extremely involved in the early days, and again, I don't mean to say physicians were not. One of the differences between public and private sector health care was that in the private sector, everybody has like, "So-and-so is my doctor; I'm so-and-so's patient, period." And nurses are removed or disenfranchised from that relationship. You're like the maids serving that relationship.

A Progressive Tradition at Public Health Hospitals

Carr: In the public sector, in a teaching hospital and in a county hospital, medicine is not seen in that powerful way, the reason for that being economic: the doctors aren't getting paid per patient the way they are in the private sector. Nursing in the public sector also has more authority, more autonomy. Nurses are involved in training physicians. So I think that's part of the context of SFGH, and the way it all came together at that moment.

Hughes: Is that a long tradition at San Francisco General, and also at similar hospitals?

Carr: I would say yes. There is a certain fraternity--I don't know whether to say fraternity or sorority--among the major public health hospitals in the country. You'll find a lot of people who've moved among SFGH, Cook County, Bellevue, Boston City

[hospitals]. You'll find a certain progressive attitude among people who have trained in those institutions. You'll find people who have an idealistic rather than a mercenary view about what they want to get out of being a health care worker tend to go to those institutions. And SFGH, I really think, is one of the big spots in the country in that tradition, and I think it was before the epidemic.

We have people there in positions of real power and influence who are old lefties. The AIDS people are not like that, but there are some people like that. There are a lot of people who are lefties, gay, nongay, who came to San Francisco because of the comfort in the community for those feelings and ended up being doctors and nurses in the public hospital. What I'm talking about is context that preexisted, so when this epidemic came in, there was this milieu of people who could deal with it, and did. And it's no accident that it existed in certain kinds of cities and certain kinds of communities in the public rather than the private sector.

The Role of Gay Culture

Hughes: Relate the hospital culture to the gay community in the early 1980s, because that has something to add to the story too. For example, how did the situation in New York, where there also is a large gay community, compare to that here?

Carr: I was part of the gay culture in New York in the seventies and I wrote about this in one of my papers for my qualifying exam in the Ph.D. program.

In the 1970s, there was what we called the gay health movement. I told you, from 1974 to 1980 I was involved in a gay clinic. There were no exclusively gay diseases, but there were political issues around the diseases. I talked about that already; it's a big part of the context of what was already in place.

You know the lesson from this? When I lived in Israel, they talked about one of the reasons the nation survived was when they got independence in 1948, the institutions were there. They had anticipated a nation and set things up--parliaments, police, fire trucks, banks.

Hughes: This I get from Randy Shilts' book:¹ the political infrastructure was in place as well, which was somewhat a legacy of the fight for human rights, for gay liberation.

Carr: Yes, absolutely.

Hughes: Gay community ties with City Hall, for example.

Carr: Yes, absolutely. It's the history of Harvey Milk that left gay people working in the hospital in a position to say that we as workers in the hospital can demand services for our people getting sick.

Gay people flocked here, built a community here, sought political power here, for reasons that, while they couldn't anticipate the epidemic, were really the same thing. They were about stigma and oppression and not having equal access. It's all one thing, really. For instance, there was those ballot initiatives against gay teachers. Those were fought successfully for a lot of similar reasons I'm talking about: there was a context and a preexisting structure that could incorporate that and deal with it. Yes, so the cultural and political context is really important.

Hughes: Disease is in fact a mirror of society; it reflects what's going on in the society at large. And this epidemic is a perfect example of that.

Anything more on the epidemic in terms of nursing as a profession?

Carr: I think nursing is very divided right now. There's a lot of proactive stuff in nursing around HIV, a lot of writing, a lot of education, a lot of conferences. I think there is a whole other side that's a reaction against that, of people who wish it would go away.

Hughes: The epidemic per se?

Carr: Not the epidemic so much, but the people involved in it.
[laughter] There's a big part of nursing that's extremely uncomfortable with all of this. So there's a big schism or chasm.

¹ Randy Shilts. And the Band Played On: Politics, People, and the AIDS Epidemic. New York: Penguin Books, 1987.

AIDS Activism

Hughes: Nursing was a large part of the San Francisco model. You could think of the model as a reflection of the postmodern approach to things, a very multidisciplinary, multiperspective view. Has the model had ramifications beyond the epidemic?

Carr: There are people who would say, and I don't know whether it's true, that the whole movement now of people being more articulate, inquisitive, wanting to have more control over their health care, that it was AIDS patients who started that. I don't think it's true. I think that other people were doing the same thing around the same time, were just being more articulate and asking more questions and stuff. I think there's a relationship, for instance, between AIDS activism and breast cancer activism. That's about people questioning the assumptions and the breakdown of the more central, received truth about all of these things. I think there is a movement among veterans around the Gulf War syndrome that you could say is a similar thing. I do think that's a way that the postmodern interpretation is flowing out. How much that actually comes from AIDS, I don't know.

I have a sense that, while ACT-UP might have been a model for breast cancer awareness movements, I think those things would have happened without AIDS. I guess it's hard to imagine that. Well, what I'm saying is that they are all focuses of their own. I don't think there is one point that they all flow out from.

Hughes: Yes, that seems very reasonable. Well, I have more questions about the clinic itself.

Working Relationships between Nurse Practitioners and Physicians

Hughes: Connie Wofsy said something that made me think that physicians, or at least AIDS Clinic physicians, hadn't been used to working closely with nurse practitioners.¹

Carr: Oh, that's absolutely true.

Hughes: I think there was some questioning, Where are our rights? Where are our boundaries? What was your experience?

¹ See the oral history with Constance B. Wofsy in the AIDS physicians series.

Carr: I never really felt that personally, because I never thought, and I don't think now, that I'm an equivalent person in the system to somebody in Connie Wofsy's position. There is a hierarchy, and she and I have very different places in it, not in a way that has to do with her personally, but due to the structure of the medical school and the hospital. We're not equals. I don't agree with the person that says, "A nurse practitioner and a physician do the same thing." They don't. Nurse practitioners don't know what physicians know. Because medicine has power, which is basically economic, most people don't realize that physicians don't know what nurse practitioners know.

My memory is that we came to a comfortable place with it at Ward 86 by trial and error. J. B. and I were both very happy to work with physicians in the context that they wanted us. It was like, they were running the program, and we were minding the store.

Hughes: Did they indeed give you quite a bit of independence?

Carr: Yes, quite a bit, and it was wonderful. I loved it. It made it so heady and exciting and so intellectually and emotionally challenging to be a nurse practitioner. You really had to know what you didn't know, and know when it was time to go back to them, because we were not physicians and we didn't know medicine.

Hughes: It was usually clear to you when that time came?

Carr: I guess it must have been, because I never got in real bad trouble around it. But so much of it was interpersonal, and about relationships--the patients were young then. They didn't have that many major medical problems. Sometimes they did, but most of the time AIDS was their only problem. AIDS was something that you could learn and manage.

Hughes: And yet, there were so many puzzles about the disease. For one thing, the very cause of it was unknown.

Working in the Epidemic: A Transcendental Experience

Carr: I worked in the clinic one and three quarters to two years, until the virus was discovered.

Hughes: Was it an unusual experience to be doing so many new things at once--working out your relationship with the physicians, learning about new facets of this disease--

Carr: It was war. It was transcendental. You didn't question it; you just did what had to be done. It was the trenches.

Hughes: So it was an extraordinary experience. It wasn't quite like anything else you'd ever done in medicine?

Carr: No, it certainly wasn't.

Hughes: And you were aware of that at the time?

Carr: Oh, yes, very much so. I knew then that this was an extraordinary time in my life, and that this was transcendental. This was the thing I would talk about in fifty years the way my father still talks about World War II. [laughs] It was war.

Hughes: You knew that at the time?

Carr: Yes, absolutely.

Assuming the Epidemic to be Short Lived

Hughes: What did you think about the duration of the epidemic?

Carr: I thought it would be over. One of my great secret dreams in life has always been to be interviewed by Terry Gross on NPR [National Public Radio]. I just love her; I listen to her every chance I get.

In '94, on World AIDS Day, on December 1, she interviewed Marcus Conant. And he said, "I remember when we thought this would be like Legionnaire's disease or toxic shock syndrome. We would work with it for a while, find the cure, it would be gone, and we would move on." I'm paraphrasing his words because I don't remember exactly what he said. And that is indeed how we felt. I thought I would be there until the end, that it would be over, and that I would go on to something else. And for me, the "something else" was going to be a much lower-tech, storefront or community-based, nonhospital-based clinic, serving gay men.

Hughes: What was the basis of your certainty that it was going to be short-lived?

Carr: I don't remember. Part of it was probably a coping mechanism, to deal with the fact that these people were really dying. It was so unbelievable that these people died. I mean, they died from a

sexually transmitted disease. Had Legionnaire's happened yet? I can't remember.

Hughes: Legionnaire's was 1978.

Carr: Toxic shock definitely had happened, and they discovered a bacterium, and they treated it with tetracycline or something. So that was the context, too.

Hughes: So there was a faith in modern science and medicine.

Carr: Oh, yes, absolutely. We were still part of the antibiotic generation, the post-World War II generation. We were the first generation brought up, as people and as health care providers, in the age of antibiotics.

In my life, as you can see [gesturing to his living room], I have pleasant surroundings for myself. But among the people I know and in my work, I'm surrounded by all this real suffering. And I think to myself, How different is this? Is this something unusual, or was I brought up with unusual assumptions about what human life would be like, because of that post-World War II middle-class antibiotic et cetera phenomenon that was really very brief. And here I am living like people have always lived, with suffering around me, and the difference is that I was sold a bill of goods about what my life was going to be like. Going to Israel and meeting Holocaust survivors helped with that sort of thought, too.

Physicians' and Nurses' Attitudes to Dying Patients

Hughes: How did you deal personally with early patients who were very sick?

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Carr: --[Physicians] were locked into the military metaphors. And I think in medicine, they taught physicians, "You're going to win every battle." In nursing, I was actually taught, "You're going to take care of some people who are going to stay sick and die." So in a way, I thought maybe I was better prepared than the physicians.

I'm not thinking so much of Paul Volberding and Connie Wofsy now. I'm thinking of the physicians who I really discussed this with on a personal level--some of whom are still my friends--who

were more my peers in the clinic, the ones who were residents and fellows.

Hughes: Was it in their eyes a personal failure when somebody died?

Carr: I think they had that view more than the nurses did. I think we nurses had some notion of, We're going to take care of sick people who die. And so we had that whole issue of dealing with suffering, and giving people quality time when you could. I remember I had those notions in my head very early. I don't know what year I said this, but I remember that I used to use the phrase, "small victories." You knew what the overall course was, what the overall trajectory of the disease was going to be, but you could keep people out of the hospital; you could keep people feeling better; you could deal with a fever; you could help people breathe better, blah blah blah.

Patients' Attitudes to Illness

Hughes: Did most people come to the clinic with fear in their eyes, or was there a bewilderment about what was happening to them? I'm thinking of people who had overt symptoms, not the worried well.

Carr: I'd say if there was a trend in those days, it was a series of reactions starting out with, "I'm gonna lick this thing; even if other people died, I'm gonna be different." And moving from that into more the "small victories" mentality: How can I keep going? It was an [Elisabeth] Kübler-Ross kind of thing, where people would move in and out of different phases.

There are a lot of people with HIV and AIDS who never seek the kind of care that we offer, because I think underlying it all is belief system. I hate the term "Western medicine," but if they didn't have some underlying belief in that, they just didn't come. There were people with AIDS who just never came, who did other things. Recently, we had a man who had a very bad tumor with a very bad prognosis, and he just refused chemotherapy and did nothing. It felt to me like he used the tumor to commit suicide. But he just had no faith and no belief. So ultimately, like everything else, it's belief system.

When I used to work in a private hospital as a staff nurse back East in my early days, and they used to have patients with arthritis who came in for gold injections into the joints, I used to say, "All healing is faith healing, and this is the treatment for people whose faith is that it has to be expensive to work."

[laughter] And I still feel that people come to what they believe in, and if they don't believe, they don't come. Somebody who comes to me and takes a lot of pills might not go to an acupuncturist.

I think the alternative health care movements have a more organized response now than they did in the early days, when we at the clinic had our organized response. There was a period of time--and this is a factor in your question about the patients coming, too--when Ward 86 was the only ballgame in town, and it certainly is not now.

Very early on, as always and as is still the case, our progress against opportunistic infections is better than our progress against the ultimate viral infection. So before there was Pneumocystis prophylaxis when there was a very high incidence of that, the word got out that we could cure pneumonia. Back when there was a large amount of Kaposi's sarcoma, we were using chemotherapy very early on, and the word got out that we could, in some people, make their lesions get smaller or hurt less. So that was really offering people hope when there was nothing else, and those were the small victories.

Hughes: When did there become alternatives to the clinic?

Carr: Oh, it's a slow, evolutionary thing. The person to talk to is Donald Abrams. I was aware of alternative therapies very early on, because when I was working in the clinic in the early days, before the virus was discovered, I used to go for acupuncture and get treatments that were geared at strengthening my immune system, because I was a gay man working at the clinic. We didn't know whether we were going to get it.

Clinical Trials of AIDS Drugs

Hughes: You were involved with a clinical trial with Connie Wofsy. Right?

Carr: Connie Wofsy was the principal investigator in ansamycin, the drug called rifabutin. That was not a clinical trial per se as much as supplying an experimental drug to people with particular diseases.

Personal Reactions

Carr: In the sense of a controlled trial with a placebo, I was the blinded clinical monitor in the first AZT trial. That was '86, I think. That was a profound experience that both reinforced and at the same time shook up my faith in medicine in ways that I still think about. Why have I made the choice to get into this really somewhat impressionistic, qualitative, social science research rather than follow into clinical trials the way so many of my colleagues have done?

Hughes: Do you want to comment further?

Carr: Well, like everything else, medicine is a belief system. Science is a belief system. Trials are a belief system. I don't have a monolithic position. I think sometimes they are appropriate; sometimes they're not. Some studies, the goal is to know whether one drug works better than another one in a statistically significant way; some studies, the goal is to understand people's response to the drug. They're not the same study; they're not the same methodology. I'm talking like a graduate student, sorry. [laughter]

Hughes: That's all right. You are a graduate student.

Carr: Now sometimes, we're doing fifty, sixty, seventy, eighty clinical trials at the AIDS Clinic. People who come to the clinic to visit are dazzled by it. "How many trials are you doing? That many?" And there's part of me that questions that. A lot of these trials haven't worked. We don't have the answer. We're barking up the same tree over and over again.

I don't know what else to do, and in many ways, we do have the answer. The patients get so many fewer opportunistic diseases, because we prophylax as a result of those trials, because we treat quickly and early as a result of those trials, et cetera, et cetera. AZT was subjected to all those clinical trials. And now, after ten years, some trials say it makes a difference; some trials say it makes no difference at all. So it's very hard to know.

That's why to me it boils down to belief. I don't know if there are any clinical trials that coordinate the patient's belief and the religious significance of taking pills with their response to the drugs. What is medicine? Ultimately it's a belief system, and I don't know how I feel about it. I would never tell people not to take medications or participate in trials. I probably

write thirty or forty prescriptions a day for these drugs that I'm questioning now. It's not that cut and dry.

Participant Recruitment

Hughes: Is there a story around recruitment to clinical trials?

Carr: It's really gone in phases. John Stansell uses a term, therapeutic nihilism. In the early days, people were crawling all over each other to get on these drugs. After that European study of AZT called the Concorde study came out in '93, which lasted longer than any of the AZT studies that were done in the States, and said that it made no difference, there was a period when it became extremely difficult to recruit people for any clinical trials. In fact, numbers in the clinic went down, because people started moving away from these drugs. That was the period that John refers to as "therapeutic nihilism."

Then there started to be all this news based on lab research of the new drugs--3TC, the protease inhibitors. This was before the baboon story,¹ which is really just the latest chapter. When those things started to come down the road and become available, and it was like something new and different, people started coming back. And now I think trial recruitment is up again. It goes in waves.

The media in many ways has done a terrible disservice. Things that show a little bit of promise in the test tube, where the real message is, Maybe we should investigate this further, and then it's in the newspaper as a new AIDS drug. Sometimes it's criminal, the false hope that gets dangled in front of the patients to sell the media. A lot of times, you feel like you're this gatekeeper who's pushing people away, keeping people away from these drugs that they have the perception that they want, need, or are going to help them, when that's not the truth at all. And that's a very painful thing.

¹ In December 1995, a research team from UCSF and the University of Pittsburgh transplanted baboon bone marrow cells into a man with AIDS. Although the baboon cells failed to grow and function, the patient improved, for reasons not entirely understood. (Lawrence K. Altman. Baboon cells fail to thrive, but AIDS patient improves. New York Times, February 9, 1996, A8.)

Alternative Therapies

Hughes: Was there any attempt by the clinic staff to keep patients off alternative therapies?

Carr: No. I think we were always right from the start pretty open about alternative therapies. There were some alternative therapies that didn't make any sense. There was one thing that to this day always upsets me about alternative therapies, and it's when people charge the patients money for things that are not of proven value. I understand that people out there in the community may have something they believe in, and they just don't have the resources of the university to be able to offer it the way we can, and the university's interaction with drug companies and state and federal money, et cetera.

I have a lot of patients on experimental treatments, a lot of people who are still using DNCB, a lot of people who go to acupuncture, and I think I've always been pretty open about it. I used to joke with people I could trust to get the joke, I used to say, "I know all about Eastern medicine. I went to nursing school in New York." [laughter] But I think there are more alternative practitioners in this town and in the history of this epidemic in San Francisco who have told patients not to come to us than we have told people not to go to alternative practitioners.

Hughes: Is there an economic motivation to that?

Carr: Possibly. Although it's getting better, partially because of Donald's work, which is bridging that gap by doing the joint studies with the alternative providers [the San Francisco County Community Consortium]. I tell patients that the controlled clinical trial is the University of California's religion, and that's the word I use, and they all get it. Nobody has ever not understood that. [laughs] And I say, "If something has not been through these trials, I can't give you an opinion about whether it works or not. And when we give you something that's just going through these trials that's not proven, we admit it." So I try to communicate to people, "There are not answers, but there's a standard of how to go about finding the answers."

I remember I told one patient, "If the acupuncturist wants to treat your symptoms, I really encourage you to try that. If the acupuncturist says they're going to cure AIDS, put your wallet away and leave immediately." And that's still what I feel now, and what I would say to somebody.

Primary Care and Specialty Clinics

Hughes: The KS Clinic, the clinic that was set up largely by Marcus Conant, and then Paul Volberding came in later as co-director, was not a continuity of care clinic.

Carr: That's true; it wasn't initially.

Hughes: Do clinics usually provide continuity of care?

Carr: The way academic clinics are set up, there are primary care clinics and specialty clinics, where you would go for a consultation. Paul was an oncologist, and he originally set up an oncology clinic, which by its nature up to that point was a specialty or a consultation clinic. He did not expect people to come to be his patients. He expected patients of other doctors to come to him for cancer diagnosis and chemotherapy, and he would communicate with the other doctor and the patient, which is the way it's still done. I send my patients to the specialty clinics very frequently, and the expectation is they'll work on a certain problem and come back to me. A lot of times, if the treatment is ongoing, such as a medication, they'll recommend it and then I'll continue to supply it over a period of time.

By the time I came in in late '83, I think it was called the AIDS Clinic, and it was rapidly becoming a primary care clinic. In the early days, we did see people who had other primary care doctors. Paul and Donald really taught us how to communicate with the other doctors, when a patient had another doctor. We would write a letter and make a recommendation, in the way that specialists or consultants do.

The Contracting Private Medical Sector

Carr: Now I have very little example of that; very few AIDS Clinic patients have primary doctors elsewhere. I still write the letter if they do, but it sure doesn't happen a lot. It's a combination of the changing social class of a lot of people who get AIDS. It's a combination of the contracting private sector. There aren't doctors who just have an office where you can go and pay ten bucks for a consultation any more. It just doesn't exist. Back then, there was still some of it, and the gay community and other minority communities were the tail end of where it still existed.

Hughes: And that situation has died in the gay community?

Carr: I would say that it has, yes. There used to be gay docs who you could go to for an STD, because of the, quote unquote, sexual revolution in the seventies, gay men needed a little more health care than other young people. So some docs had episodic care practices, where you'd get what you had treated and pay ten bucks. As people began to get early HIV or frequent STDs or whatever before that, these doctors were already evolving into primary health care docs. But now the doctor who just has his office in a second story over Castro Street and everybody pays cash or writes a small check doesn't exist any more.

The AIDS Clinic's Reputation

Hughes: Do most patients come to the AIDS Clinic because San Francisco General is the county hospital? Or are patients knowledgeable enough to know that they have AIDS or HIV disease and should be seen in the AIDS Clinic, which has quite a reputation?

Carr: It's a combination of things. We do have this reputation in the community and nationally. We still to this day, not as much as before, have people moving to San Francisco from all over the country to get public health care here, because they know they have HIV. It has to do with the reputation of the clinic.

The summer before last, my partner, Matthew [Chapman], and I went back East for the twenty-fifth anniversary of the Gay Pride Movement. We were in New York and Provincetown. I had three instances where people walked up to me in public and said, "Aren't you from Ward 86?" So people know Ward 86. When you go all over the country, if you say Ward 86, people know what you're talking about, and other countries as well. So part of it is our reputation, yes. It's so lofty and so funky at the same time. Because at the same time we have that reputation, we're also the county clinic; we're the clinic of last resort for people who have no resources and no money.

Hughes: Right, this is the only place they can go.

Carr: The place where they get turfed to is the same place with the worldwide reputation. I think that's great. I've always been proud of that part of Ward 86, that we're the last resort and we'll take anybody. And we still do. I've always been proud of that, and I'd say that most of the staff feel that way.

Founding the AIDS Service at SFGH

Hughes: When did you arrive at the clinic?

Carr: December 5, 1983.

Hughes: So both the clinic and the inpatient ward were established, although not for very long.¹ Did you fear that they would become leper colonies, by segregating AIDS patients?

Carr: The need to treat these people in a comprehensive way was greater than the fear of stigmatization. Although it's no accident that Ward 86 is on the farthest corner from the center of the campus that you can be. The building [Building 80] across the street from the campus center that we're in contains the AIDS Clinic, the refugee clinic, the tuberculosis clinic, and the methadone clinic. [laughter] That's not an accident. It gives that building a funky spirit of its own. So there were big powers that be--.

That building apparently sat empty for many years during the seventies. I think they built the new building in the late sixties and opened it in '69, '70, something like that. Between when the new building opened and when Ward 86 started, I think big parts of that building sat empty. When we moved in there, Building 90, the back part of the building, was not in use, if I recall. I always remember at my job interview, Ward 86 had the south half of the floor, and the north half of the floor was under construction. I remember Gayling having me step over big piles of wires and pieces of two-by-fours to show me the floor.

Hughes: Which was going to be--

Carr: The AIDS Clinic. But it's no accident that it's the farthest corner away from the center. So the stigma thing was happening in a big way, on some level, conscious or not I don't know.

Hughes: And yet, the inpatient unit was, is, and had to be, I suppose, in the hospital proper.

Carr: Right. There was no question around that. There was no way around that. You have to have an enormous amount of physical support for inpatient units. You could no longer put inpatients

¹ The AIDS Clinic opened in January 1983 and Ward 5B in the summer of 1983.

in those old outlying buildings, although they all were wards at one time. Have you ever watched the old black-and-white TV show, "The Streets of San Francisco", where Karl Malden is an older, smug San Francisco cop, who reminds me of [ex-]Mayor [Frank] Jordan?

Hughes: I've heard about it.

Carr: There were a few episodes where Karl Malden goes to San Francisco General Hospital, and they show him on the steps of Building 80, because Building 80 was empty in the seventies when they were making that show, and they could use it that way. It's very funny.

Giving Nurse Practitioners Authority to Diagnose AIDS

Hughes: Whose responsibility was it to get it across somehow to a patient that he or she indeed had AIDS or HIV disease?

Carr: That was always a function that was equally shared among all the workers, and in fact, my most specific, vivid memory of my first day at work there, on Monday, December 5, 1983, was Paul Volberding saying to me, "Use the words AIDS and cancer. Use the words." That's my most poignant memory of what Paul Volberding said to me that day. There were many times when I had to stop myself for a minute and say, "Use the words."

Hughes: Why did he instruct you in that way?

Carr: He was giving me the authority, the judgment, the recognition to tell people. For a nurse practitioner in those days, for any nurse, that was still a big deal. There's a long history in nursing, you're not supposed to tell the diagnosis. It was a big change, it was a big deal, it was a big part of what made it heady, that from the first day, I had the authority to talk to patients as an autonomous health care practitioner, not as being under anybody else. It was a big deal, Sally. Yes. Is that the question you were asking?

Hughes: Yes, but I want to explore it a little further. Some of that is Paul's less hierarchical way of running his life. I get you completely that there still is a hierarchy in medicine, but there are greater and lesser degrees of hierarchy.

Carr: Yes. It was by fiat because Paul is Paul, yes. It wasn't because that was what nurse practitioners could do, it was because that

was what nurse practitioners do because Paul let us, and to some extent, it's still that way.

Cultural Attitudes towards Discussing Fatal Diagnoses

Hughes: Where does the patient and his or her sensibilities enter into this? I understand that to this day, for example, it is common practice in Japan not to tell a patient that he or she has cancer, ever.

Carr: Yes, right. It's a big cultural issue, and it's a part of what was changing here in the sixties or seventies in terms of some of the politics. That's one of the things that was culturally changing in the U.S. at that time. In my family before that time, you didn't talk about the diagnosis. I didn't tell you the story about my Aunt Ida, did I?

Hughes: No.

Carr: What when I was in nursing school, my father's sister was dying of metastasized breast cancer. She told everybody in the family she had arthritis. I was a student nurse and went to visit her in the hospital in Patterson, New Jersey, and she was lying there with chemo[therapy] running and a chemo cap. I looked her in the eye and I said, "I'm a nurse. Are you going to tell me you have arthritis?" And she said, "Yes." Everybody knew what was going on, of course. She died with such isolation from her family because of everybody's uncomfortableness about the truth.

I think of my Aunt Ida when I have to tell somebody their diagnosis and it's difficult, and why it's better to say it, and know, and deal with it.

Hughes: Is there any pattern?

Carr: Who to tell, how to tell, when to tell, is a big part of that judgment and autonomy I was talking about before. There's no one way to do it. You don't always do it the same way. But what I'm really convinced of is, you do always do it. Boy, talk about the art, not the science of medicine. I always do it when I have to do it. When people say to me, "Is this a terminal disease? Am I going to die from this?" In one way or another, I say, "Yes." It might be one syllable, "Yes." It might be talking half an hour, "Yes." It's a lot of judgment.

I have grown so much as a person and seen so much as a person and been such a person, and gotten over to some extent--not as much as I wish--the bullshit in my family that led to situations like Aunt Ida. I feel that's the hook in my psychological-cultural background.

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Carr: All the older people in my neighborhood when I was a kid, who spoke with funny accents, were Holocaust survivors but didn't talk about it. And so I grew up with this thing about stilted, noncommunicative, dishonest relationships. So sometimes when I think about that, I think it's no accident that I grew up to be a person who tells people they have cancer and AIDS.

I was immediately given the judgment and autonomy to do that, and that's one area where we [nurse practitioners] were brought in as primary health care providers immediately. And it was one area that was pretty nonhierarchical. But yes, it is because of Paul.

Lymphadenopathy Patients

Hughes: Well, in July of 1983, which I realize was a little before you came to the clinic, Donald Abrams came in with his caseload of lymphadenopathy patients, about 200 of them, I understand. That's a lot of patients. What difference did that make in a practical sense to the functioning of the clinic, and also regarding political clout, since hospital administrations tend to look at things in terms of profitability?

Carr: Number one, Paul structured the clinic so we were still a UC clinic, and we were all UC employees. So to some extent, the economic thing, and with the value which the university placed on research, because Donald was conducting research, was absorbed in that whole set of assumptions.¹

The other thing was, in those early days, we didn't have that high a volume of patients, and unlike now, our week was not entirely structured. There were certain clinic sessions at certain half-day periods of the week. I think I told you, one half-day was KS Clinic, one half-day was opportunistic infections. Those distinctions are now all blurred. But in the beginning, it

¹ For more on Abrams's research on lymphadenopathy, see his oral history in the AIDS physicians series.

was like that. So when Donald came, they took a half-day that they weren't using and set up a new clinic for lymphadenopathy patients. So absorbing the people was not that difficult.

On the economic side, it was number one UC and number two research, and on the logistical side, there was empty time in those early days. So Donald started a new clinic. When I first came, I worked with Donald on Tuesday mornings, and I cut my teeth a lot seeing his lymphadenopathy patients. He had lymphadenopathy data collection sheets, and I learned how to examine those patients, see whether their lymph nodes had changed, chart the lymph nodes on the sheet that eventually became the data, order and interpret the lab tests. One of the ways I cut my teeth was working directly with Donald.

In the early days when I first started doing it, I presented every patient to him, told him what I found about their lymph nodes, and then he would come in and reexamine the patient to make sure my exam was accurate.

Infection Control Procedures

Hughes: Were there changes in infection control procedures as time went on?

Carr: Not really. I'd say the biggest change in infection control had to do with tuberculosis, and that came later. I was told by both Connie and Andrew Moss, the epidemiologist, right away early on, that this was clearly caused by a virus, and that that virus was transmitted the same way as hepatitis B. So the precautions in the clinic were hepatitis B precautions right from the beginning, and that never really changed, and it turned out to be absolutely true.

Hughes: Did that mean gloving when--

Carr: Gloving when it was appropriate. But no, we certainly did not wear gloves to touch people. In those early days, when I measured Kaposi's sarcoma lesions with a tape measure, I did not wear gloves. Those lesions were dry. There was no exudate or fluid on them. It was just like touching skin. There was no reason to wear gloves.

Hughes: Is that still true?

Carr: Yes.

Hughes: Connie Wofsy talked about an effort on the part of certain members of the staff to bend over backwards to indicate to the patients that in no way were they--

Carr: Scared of them. Yes, I was one of those people. I absolutely would not have worn gloves more than when they were indicated in any nursing situation. It was very important then, to give that message to the patients. It was the same thing on the inpatient unit. There were people who wanted to gown and glove much more than was necessary, but it had to do with their own notions of stigma. They weren't afraid that if they got AIDS they would die; they were afraid that if they got AIDS, people would think they were gay. That's what that was about. It was stigma, yes.

Back in the early days before there were AIDS educators, I was once teaching a class to the prison guards at YGC, the Youth Guidance Center--talk about euphemisms--and these guys were fidgeting in the back like junior high school kids--all these cops and firemen who got so crazy around AIDS. These are people who walk in front of guns, who run into burning buildings, and AIDS made them crazy. Why? Same thing over and over and over again.

Hughes: Were people ever hesitant to glove when they really should have gloved?

Carr: No, I don't think so. I don't remember feeling that way. I remember explaining to patients why I was going to put on gloves at a certain moment. As a nurse practitioner, I have to put on gloves much less than a staff nurse does. I don't start IVs [intravenous lines] or do invasive procedures that often. People don't ask that much, if you just glove when you would ordinarily do it. But no, I was never afraid to touch the patients. When I was a staff nurse in 4D, the trauma unit, and they started bringing in gay men with pneumonia, some of the staff wouldn't go in the rooms, but I always did.

Hughes: Would you have done that with anybody, even if they weren't gay?

Carr: That's a good question; I don't know. It was gay men, so I did it, and that was a big factor. Would it have been other people? I think so, but I don't know.

Hughes: Well, you can test that now, because of--

Carr: Tuberculosis?

Hughes: Yes.

Carr: If that's the example, then I would have done it, yes. Because I have gone in to my patients on TB precautions without a mask on, to try to communicate a certain feeling toward them.

Hughes: Be careful.

Carr: Yes, I will.

AIDS Education

Hughes: Was education built in to your functions as a nurse practitioner?

Carr: In the clinic?

Hughes: Yes.

Carr: Now, we have a very structured education program. In the early days, it was all strictly interpersonal, one-to-one. Now we have scheduled meetings and lectures and presentations, but in the early days, we didn't really have that. We just talked among ourselves.

Hughes: That's a good answer, but I was actually thinking in terms of patient education. Was there any structure to that?

Carr: Now there are people whose job it is to do this. But back in the early days, I participated in seminars for the patients and things like that. I think I told you the story about the first time I ever saw Paul and Donald.

In the mid-eighties, we did presentations for patients about the nature of the clinic: what to expect, how the system worked, who to call for an emergency. And I remember we had a few meetings in Carr Auditorium at the hospital where we invited the patients to come and hear presentations. That was fun.

Hughes: How is that sort of thing handled now?

Carr: I don't think there is such a thing. The people who are doing education now have talked about making a video about the nature of the clinic and playing it in the waiting room, but there's really no such thing right now. Things travel so much by word of mouth.

When I see new patients, I explain certain things to them: how things work, that we work by appointment, what to do if you have an emergency, who to call. I try to explain that to new

patients. I don't always do it within the first visit. Sometimes it takes me the first few visits. But it's something I still try to do.

Hughes: And does the word spread as well, now that the population with AIDS is more diverse?

Carr: Yes, the word spreads as well.

Hughes: And it spreads within each of those communities?

Carr: Yes, because although there's a diverse population, one of the things that unites a lot of the people who we might call diverse is their connection to the intravenous drug use culture, and boy, do things travel fast over the grapevine in that group.

Expansion of the AIDS Program at SFGH

Hughes: It was Gayling who said that there was some staff unease when Paul began to spend less time in the clinic because of the press of other obligations.¹

Carr: Oh, yes. As it became more of an organization and a program, and Paul started being away from the clinic, yes, that's really true. I never felt that so much, but I remember one time he was upset because people had been sarcastic with him about how he hadn't been around much. But the whole thing was expanding so rapidly, and it was becoming a program with multiple clinics, with different kinds of services; he was getting involved with the international AIDS conferences as they were starting, yes. I thought J. B. and I understood that, because in a way, it enhanced our role.

Hughes: It surely did.

Carr: I see the AIDS program as having many different functions, and the one that I'm concerned with is the clinic.

Hughes: You had to do that even more and better, if there was one key person [Volberding] missing.

Carr: Yes, that was true, and there were long periods of time when we wouldn't see Paul and wouldn't know where he was. But we always

¹ See the oral history in this series with Gayling Gee.

kept going. That still happens. Today, there's supposed to always be a supervising physician called the attending physician there at all times. Today, the physician who was supposed to do it had been back East and couldn't get back because of the snow. And there was no physician in the clinic, and we just carried on. It was the same thing: some people bitched and moaned about it, and some people said, "Well, this happens; we carry on." [laughs]

I feel like I have a good enough reputation among the physicians that if there's nobody there, and I go to one of the other physicians and say to them, "There's no attending; I really need help," I feel like they'll stop and deal with it. Because they know that I can bear a lot and keep things going without asking that, and if I ask, I must mean it.

Part-time Clinic Physicians

Hughes: I wonder if you'd care to say something about Steve Follansbee's role.

Carr: He's been at the clinic ever since I have. Steve is in private practice, and now there's a formal HIV institute-type thing set up at Ralph K. Davies Hospital, and he's the head of it. It's to coordinate the clinical trials they do at Davies. When I first met him, I believe he was in private practice on Army Street and admitted [patients] to St. Luke's.

But he's always worked at the clinic two half-day sessions a week for my first five or six years [1983-1988/1989]. He used to work Monday and Thursday, and now he comes in one half-day a week on Monday. He's done it very, very regularly.

Hughes: Is he a volunteer?

Carr: No, he gets paid by the university. Gifford Leoung does it, too. Gifford is also in private practice. He admits to St. Francis Hospital, and he's chairman of their HIV institute. Gifford was a fellow in the AIDS Clinic and then a full-time employee in the early years. Both Steve and Gifford come in and attend, supervise. They don't really see patients directly; they supervise the rest of us for one half-day a week each. They do get paid.

I think the basic reason that they both do it--I don't know this; it's my suspicion--is to keep some affiliation with the university so they can use their adjunct assistant professor

title. But they both enjoy it and have fun, and I think that private practice can be a little isolating. I think they both get a little rejuvenated by hanging out with the group. I don't think of either of them as ethereal at all. To me, they're both like my friends for many years. In fact, Matthew and I get together with Gifford and his wife for dinner sometimes.

Hughes: Well, the AIDS Clinic is a very multidisciplinary clinic, but I'm gathering that it was in no way the first experience that you'd had with multidisciplinary.

Carr: Right.

Hughes: Was there any difference?

Carr: Oh, yes. My clinic back East was a completely independent storefront clinic. We collected money from patients to support ourselves and got small, partial grants from the feds and the city of New York. And we ran it. We called ourselves a board of directors, but we were basically a collective, and it was our sixties political principle that everybody was going to be equal, whether they were licensed, nonlicensed, physician, nurse. We really struggled around that. We were probably really hard on the physicians when they acted like physicians.

The AIDS Clinic, as I told you many times in our interviews, is quite hierarchical, and collegiality does exist and it is real, but it's still by fiat. And an institution like this, in the context of the university and the teaching hospital, et cetera, there's no way it could be otherwise. If Paul left and somebody came in, and he didn't want it that way, he could change it, or she. I think a lot of us would probably leave. But it's still by fiat.

To some extent, the world is that way, and as a nurse practitioner, you're never going to be the chief in a medical situation. So the best advice is to go with chiefs you can trust and feel good about. And that's what I'd say that really a lot of the staff would say.

Hughes: Did you have any particular reaction when you saw women begin to attend the clinic?

Relationships with Patients

Carr: Oh, I'm not comfortable about this, because I was uncomfortable about working with women. I wanted to work with gay men.

The two women nurse practitioners, Lauren Poole and Catherine Lyons, always right from the start put themselves out as being interested in women. So the reason it never became a major problem was because we all had our own little community-based identities. I still get more gay men than other kinds of patients, and it's because of who I am, how I'm known in the community, who asks for me, whose friends tell them to ask for me. So I've never taken care of that many women.

I was working with a woman a year or so ago, and she had so many complex social service needs that she was too isolated working with me. The only way to take care of her was to have her start coming in for the women's clinic, where there's a structure to meet all these social service needs. The clinic hooked her up with a social worker, and she started coming in to the women's clinic, and the next thing I knew, she bonded so much with the women's clinic, that she'd shifted over to being Lauren's patient rather than mine.

I don't have bad feelings about that, but it's an example of the way things tend to gravitate. So it's to some extent my desire, and to some extent self-fulfilling that I'm there for gay men. There are those subcultures in the patient population. So I end up taking care of a lot of gay men.

I did have difficulties with women at first, and I wasn't comfortable with it. It wasn't so much anything against women as I had an agenda, and that wasn't it. At the same time, the women at the AIDS Clinic are feminists, and they put out for the women, and so they see the women. It's also sort of postmodern, all that multiple protocol.

Hughes: Do these agendas, if that's what you want to call them, work pretty harmoniously, one with another?

Carr: My sense is that they do. It can happen for a lot of different reasons. But I think there's a lot of referral and exchange of providers and patients back and forth. Patients change providers; providers change patients. I can't ever remember rejecting a patient. But sometimes, you're having some kind of conflict and things are not working well for whatever reason. Sometimes it might be somebody who wants to take a lot of narcotics and I don't think it's good for them to take that much. Sometimes it might be

somebody who really doesn't want to do antiretroviral therapy, and they feel like I'm really nagging them too much to take it. It might be any one of a number of things.

But there's a certain amount of drift. I've picked up on patients because they came in to see me as a drop-in patient, and they liked me, and they switched to me. I've lost patients in similar ways. I lost a patient I really liked, and it hurt me to lose him. He had tremendous denial about his disease, and I confronted him with it, and he ended up leaving me and going to another nurse practitioner. I think he wanted me to order his T-cell count more often; that's what it was. I don't think the other person he's seeing does, but for him it was this conflict with me.

Hughes: Well, it was part of his denial.

Carr: Yes. And I confronted him. I have this concept I use that I call traditional cultures, because whether it's Asian, Latin American, Hispanic, Eastern European, Jewish, myself coming from a large Yiddish-speaking family in New York, there are people who are connected to some foreign culture background who have shame about their families, and I include myself in that too. You just see this universal pattern of shame and denial and stuff about disease. I would be one of those people; I know that I would. My heart goes out to them.

But at the same time, I've had incidents where I've destroyed relationships with patients by being a little too confrontive, and saying in some way or another, probably without using that word, "You've got to get over this shame."

Hughes: And they weren't ready.

Carr: Yes. And that's basically what that conflict about the T cells was really about.

The AIDS Screening Clinic and Diagnostic Algorithms

Hughes: The AIDS screening clinic opened in the AIDS Clinic in February of 1983, which was, of course, before you were actually employed there.

Carr: Right, Gayling and Tracy [Moran] did it.¹

Hughes: Right. How novel an idea was it to have a screening clinic?

Carr: Oh, it was a very novel idea, and even for all the years that I did it, it was a very exciting thing and there was nothing else like it as far as I know. For the most part, it was before the antibody test existed,² and it was again a response, like the lymphadenopathy and the ARC thing, to the fact that there were clearly people who did not have what we were calling AIDS who had this disease. Every gay man was walking around--

Hughes: Wondering.

Carr: Yes. The screening clinic was the most state-of-the-art assessment that was available at that time.

Hughes: Anywhere?

Carr: Probably, yes.

Hughes: In New York, too.

Carr: Yes. As far as I know, it was the first thing that so directly addressed the fact that we knew that there were people who "had it," quote unquote, who didn't have AIDS-- And how to deal with them, and how to give them service that they could relate to.

Hughes: I read--it must have been in one of your articles--that there was a system of algorithms.

Carr: Right, it was in two places. It was in my chapter on ARC in the Gee and Moran book, and then it was published as an article authored by me and Gayling in the journal Nurse Practitioner in 1986.³ Yes, those algorithms still exist. They're basically pretty much the same.

¹ For more on the screening clinic and other aspects of the AIDS Clinic, see the oral history in this series with Gayling Gee.

² The AIDS antibody test became commercially available in March 1985.

³ G. S. Carr, B. Newlin, G. Gee. AIDS-related conditions. In: AIDS: Concepts in Nursing Practice. G. Gee and T. Moran, eds. Baltimore: Williams and Wilkins, 1988, pp. 104-122; G. Carr, G. Gee. AIDS and AIDS-related conditions: Screening for populations at risk. Nurse Practitioner 1986, 11, no. 10, October.

Hughes: Did you devise those?

Carr: I actually wrote them down, but they were a product of the clinic practice. At the time Paul, Donald, Connie, Gifford, all reviewed them. I discussed them with all of them.

Hughes: And it was the system everybody was using?

Carr: Yes. And it still is; it hasn't changed that much over the past ten years.

Hughes: You made the point in the chapter that the algorithms moved from least invasive to most invasive.

Carr: Right, also least to most expensive.

Hughes: Exactly, you made that point too. [laughter] So there was a dual purpose in using the algorithm.

Carr: Yes. That part of the algorithm was for system-by-system assessment, looking for diagnosable disease.

Hughes: Anything more to say about the screening clinic?

Carr: It was a really good, exciting moment for nursing. It broke my heart when we stopped it, but it was appropriate then in terms of that movement toward being a primary care clinic and integrating everything into one. It was around the time when artificial distinctions between different kinds of patients, based on their subdiagnosis, were becoming obsolete. So I understand why we did it.

I still do it all the time. In most of my clinic sessions, there's one that we call "new patient slot" that's a little longer in terms of number of minutes than my other slots, and in which I'll see somebody new. What I do, what I say, the way I examine them, the tests I order, are all basically exactly the same thing as I would have done in the screening clinic way back when. There are historical differences. For instance, now, most people will have already had an HIV test--although not always--and most of them will have already probably at some point had a T-cell count done. Many of them will already be diagnosed with AIDS. Because it's a new patient appointment, it doesn't determine the way it is used.

For instance, in the old days when we had screening clinic, people who'd had an opportunistic disease would not go to screening clinic; they'd go right into the AIDS Clinic. Now, somebody who comes in to a new patient appointment because there's

no screening clinic might be somebody who before would have been a screening patient, very rarely somebody who's not been HIV tested. We've never encouraged the clinic as an HIV testing site. Most people are tested elsewhere, and then come in for medical assessment. But it could be any level.

I teach classes now based on the algorithm, and I usually say that--

##

Carr: The first reason is [if the patient] expects they may have HIV, the algorithm can be used. Because of some of the abnormalities that you may find consistently on routine tests with people with HIV, the algorithm can be used to help strengthen or weaken your suspicion that that's indeed the case before you HIV-test them.

Number two, if you're seeing somebody who's known to have HIV, the algorithm can be used to monitor some of the expected changes we see that may be signs of progressing disease, early opportunistic infection. And the third reason is for health care workers seeing patients who may not perceive themselves at risk, but if you perceive them possibly at risk, it may be something that you can use to help make your determination of whether you're going to risk the emotional stuff of recommending HIV testing to somebody who may not perceive themselves at risk.

Hughes: Is there any significance to the fact that the first people who were running the screening clinic were not nurse practitioners?

Carr: There were no nurse practitioners in the clinic at the time, and that's all it was. But one thing nurse practitioners can do is the physical exam, so before there were nurse practitioners, the screening clinic did not include a physical exam. It was just an interview and ordering lab tests by protocol. When J. B. and I came in as nurse practitioners, we incorporated the physical exam, and we probably added a level of judgment about what laboratory tests were ordered and their interpretation.

Relationship between the AIDS Clinic and Inpatient Unit

Hughes: I understand that at times the relationship between the clinic and the inpatient ward could be quite stormy, that there were problems.

Carr: Oh, yes.

Hughes: Do you want to talk about that?

Carr: They really function very separately. The clinic, as I said, we're UC employees, and it's basically an off-campus UC clinic at General. I think that the reason Paul did that was so he wouldn't have to go through the very cumbersome county civil service system, where, in terms of hiring, you get who's next. He wanted to have some say in hiring people who would have some kind of commitment.

The inpatient unit is part of the county, and the people are county employees. I think an underlying subtext in all of this is that the pay scales are different, and the county people make a little more than the university people. I think there's an underlying resentment about that. We're supposed to enjoy the snob factor of our academic nature, and take that in compensation.

But I think that when conflict has arisen between the two units, a lot of it has had to do with personal burnout. For instance, admissions have been questioned at times when there were reasons that had to do with staff, why they couldn't take that [patient] admission.

My perception of the conflict between the inpatient and the outpatient unit has had to do more with the medical teams than with the inpatient unit nursing staff. I was the only original staff member on Ward 86 who had been a staff nurse at General. I knew a lot of the people. I think entree into the culture of the inpatient unit was easier for me, because I knew a lot of people.

Relationships between Nurse Practitioners and Medical House Staff

Carr: But I've always had problems with the medical house officers. I think there have been times when they've had attitudes about AIDS patients--some of them--that were stigmatizing and prejudiced. I think there have been times when they were burned out and they didn't want admissions, or would be sort of rude about admissions, because AIDS patients tend to be among the harder patients to take care of. It hasn't been happening so much lately, as medicine lightens up, and frankly, as there are more women.

The new medical teams come on in July, and July and August would be this struggle when we would call up to give report on admissions. I'd say, "I'm a nurse practitioner," and there would always be some interns and residents who wouldn't want to take report from nurses, or would have attitude about it.

Hughes: How did you handle it?

Carr: It depended. There were times when you could talk it out, and there would be some times when they would be so unreasonable that you couldn't. But if it ever got to an attending level, Paul, Donald, and Connie always, without exception, defended us. And if we made mistakes, they still defended us. [laughter] So my sense is that that's just not a big deal anymore.

Part of it now is, I'm so much older than they are. [laughter] I'm just an authority figure in a way that transcends that. Part of it is, we really know how to do it, and when we give reports, our reports just have credibility. Part of it is that I think nurse practitioners are more visible and accepted in the world. Part of it is that medicine is going through power changes of its own, and it's more used to other people being primary health care providers. Part of it is that we have a reputation around the country as a pretty liberal medical school, and we tend to get more progressive students and residents. So my sense of that is that things are getting better and better.

In the old days, when I think about it now, it's funny, but there were some awful moments. I had doctors be so shockingly rude to me. I was on 5A and Diane Jones was telling a story about how a doctor sounded off at a nurse in a really rude, sexist, classist way, and the staff just silently all came and stood in a circle around him until he was intimidated. And that evolved into what they do when that happens.

Shanti Counselors in the AIDS Clinic

Hughes: Do you have anything to say about Shanti?

Carr: I have so much less contact with Shanti now than I used to. In the early days, Shanti was very important, because Shanti had paid professional staff on the inpatient unit until they lost that contract just two years ago. They stopped doing it before that-- I'd say maybe about five, six years ago--but say for the first five or six years, they had a paid staff counselor in the clinic at Ward 86. There were a few different people, and their level of competence at the job and their skill at interacting with the staff really changed a lot. The last person who had the job was awful, dishonest, and who we think now was probably coming to work high on drugs. It really ruined Shanti's reputation with the clinic in an unfortunate way.

But in the early days, I had a lot of contact with Shanti. Within my first year at the clinic, I took that famous Shanti weekend training, and that really helped me. It was back when it was in that old convent building on Fillmore and Hayes in the Western Addition.

Hughes: Tell me what went on.

Carr: It was that first guy who was with Shanti, Jim Geary, who later left in a scandal. I remember sitting around in that old convent. It was so pleasant. The main thing I remember, he did guided meditations where he took you through what it was like to die. It was very helpful in the early days. I don't know how much of it was the actual information and how much of it was just that sense of community and commonality with other people doing that work.

There was a time when we all knew each other, when everybody working with HIV in San Francisco at all the different agencies all knew each other; we all had contact. When it was a conference or something, it would be really a nice feeling. Doing the Shanti training was one of those things, going back to Shanti to teach classes for their other volunteers. I remember some of the early Shanti counselors who were very good. I used to go to them sometimes and tell them my problems, and some of them were really helpful.

I maintained the kind of relationship with one of the Shanti counselors where we really shared in a very intimate, Shanti-kind of way, right until the end of when they had the contract. She still works for Shanti, and I still consider her my friend, and we stay in touch, but the reality is now that we work in different sites and the way people's lives are, I haven't seen her in months. And I used to see her at least once a week. There would be a time when I'd walk into the staff lounge at 5A and she'd be there, and we'd have an interaction that felt good and personal and intimate.

Sometimes when I had particularly difficult patients who were being admitted, I would call her and I would say--even if I just left her a voice mail--"This one's really scared. Why don't you go say hello to him?" And I knew she would look forward to my calls, because she had confidence in my judgment about who was really needy, and my calls to her would be a particular challenge. If I called her, she knew this case was going to be really interesting and challenging. My feelings about Shanti from those old days are good.

Shanti got way too big for its britches. Gayling was on the board of directors for quite some time, and that was a very big

part of her experience. So in that way, Shanti was more a part of her experience than mine. But at the time Eric Rofes was there and those scandals were happening, I was very removed from Shanti. And now that they've lost the contract and they're not in the hospital anymore, I really basically have no contact with them whatsoever.

Hughes: Why did they lose the contract?

Carr: I think the city didn't want to be associated with them because of their financial scandals. Which is unfortunate, because they did a lot of good work and there is no equivalent thing going on now. They were professional people; they had MFCC's [Master's in Family and Child Counseling]. But there was also an informality, an availability about it that's not the same thing as psychiatry or therapy, and that the nurses don't have time to do. And my personal opinion--not everybody thinks this--is that it was a loss when Shanti left.

There were some problems with Shanti, for instance, that worker at the clinic who was dysfunctional. I think there were some people working for Shanti who sometimes were a little inappropriately personal. There was a little dating patients and stuff. And I think that there were some people who had such an agenda that they weren't professional. Like, "You're going to die in the Shanti way, or I'm going to beat it into you." [laughter]

It makes me think of some of the people who are religious who counsel people. You can't have an agenda where every patient is going to go through their illness your way. You fail. Those are the people who burn out. And there were a lot of people with Shanti who were like that, and they burned out. Although there were some who were not, who were flexible.

Self-Protective Mechanisms

Hughes: Well, you have been in this epidemic almost since its first recognition. How do you keep going?

Carr: I've been involved in a lot of different things. I've tried support groups and meetings and special support groups for AIDS staff. I have found that the best thing for me so far has been to have my life away from AIDS, and leave it until it's time to go back to work. That's my personal life here and my life with Matthew. I think I told you that until a few years ago, I lived in the Castro, and moving out of the Castro has really helped.

Hughes: Did you move to distance yourself from the epidemic?

Carr: No. We moved out here [to the Sunset District] because we wanted to move out of the city, but we didn't want to have to deal with bridges, and we wanted to keep having the political security as a gay couple of living in San Francisco County. So this location was a compromise. When I come out here at the end of the day, I feel like I leave the city in a way. We're on the last block before the ocean, and the ocean is right out there. There's another row of houses between us and it, but it's right out there, and it's very, very nice to live by the ocean. Sometimes if we're just sitting here and we're talking about going places, I'll say, "Go into the city."

Hughes: It has that feel about it.

Carr: So being far away is nice; having a life away from it is nice.

Going to school is having another life. Even though, if you add up my hours, the clinic is much more, school is this other life where I get treated in a different way. I'm in a different role; it keeps my mind active; gives me a chance to reflect on what I'm doing, and last but not least, leads to a goal where eventually, when I'm ready, I'll be able to move out of this job and into something else.

Hughes: Have you sometimes had a struggle to separate yourself from human beings who you realized were needy, but there was a limit to what you could give and keep on going?

Carr: This is a way that I've changed and grown over the years. I hate to use the word, but I think I used to be more codependent with the patients than I am now. I have much better limits and separation and I know that I can't take on everything; I can't solve everything.

Hughes: Well, do you have anything more to say?

Carr: I'm a little worried now about the effects of working in the clinic, or my busy schedule, because I've had some problems lately. I find myself really out of shape and winded, and I'm thinking, What's the relationship between this work and my inability to control my weight and stay in shape?

Hughes: Anything more, about anything?

Carr: This epidemic is definitely a candidate for history, and it's been a profound experience. For these past twelve years, part of me has been taken up and out of ordinary life, and put in this

special place. Sometimes a good special place, sometimes an awful special place.

One of the things that I've appreciated the most in twelve years is work that I can really call mine, feel involved with, feel connected to, and know in my heart of hearts has meaning. Meaning is the word.

Hughes: Well, thank you, Gary.

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University of California
Berkeley, California

The San Francisco AIDS Oral History Series

THE SAN FRANCISCO AIDS EPIDEMIC: THE RESPONSE OF THE NURSING PROFESSION,
1981-1984
VOLUME II

Angie Lewis, R.N., M.S.

NURSE EDUCATOR IN THE SAN FRANCISCO AIDS EPIDEMIC

An Interview Conducted by
Sally Smith Hughes, Ph.D.
in 1995



Angie Lewis, 1990.

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INTERVIEW HISTORY--by Sally Smith Hughes

Angie Lewis was interviewed for the AIDS nurses oral history series because of her role in the early epidemic as a nurse educator and clinical nurse at the University of California, San Francisco [UCSF]. Taking note when rumors began to circulate in 1981 of a strange skin cancer afflicting gay men in San Francisco, she began regularly to attend weekly meetings at UCSF of the Kaposi's Sarcoma Study Group. Complementing other accounts in this series, Lewis tells of the importance of these meetings as a gathering spot for the small group of physicians, nurses, and scientists initially interested in the new syndrome.

Lewis immediately saw her role as one of education--both within the walls of UCSF and in the outside community. Like so many others in this series, previous experience had "prepared" her in unanticipated ways for participating in AIDS efforts. A course she had presented at UCSF on human sexuality had given her organizational and teaching experience as well as confidence in conveying sensitive information in a manner that students could accept. As one who had for years struggled with her own sexuality and finally come out openly as a lesbian, she was particularly attuned to the plight of other homosexuals.

She describes in detail the conference she organized and presented at UCSF in June 1982, "Kaposi's Sarcoma and *Pneumocystis Pneumonia*: New Phenomena among Gay Men." Past experience had taught her the power of including "a person living with the disease" in an instructional program, a practice which she used in this and other AIDS educational programs. "The audience," she explained in the oral history, "needs to get the sense of the humanness of the disease."

Lewis's early work in the outside community was largely with the Kaposi's Sarcoma Research and Education Foundation, a predecessor of the San Francisco AIDS Foundation. She was a member of the speakers' bureau and answered callers' questions on the Foundation's telephone hot line at a time when there were not many hard and fast answers. One of her aims was to connect people with existing community services. She describes her frustrating search for city agencies willing to assist her first AIDS patient, Simón Guzman, who figures in Randy Shilts' And The Band Played On. None was willing to help after learning from Lewis that Guzman was gay and suffering from an apparently infectious disease. Her humanity shines through when she tells of going daily to sit by Guzman's hospital bed, holding his hand in silence; they did not share a common language.

The Oral History Process

At the time of the interviews, Lewis had recently retired from UCSF and was beginning a new life as co-manager of a restaurant in Forestville. She was extremely reluctant to be interviewed on the subject of AIDS, having realized only after leaving UCSF that she was suffering from "burnout" due to her long involvement in the epidemic. She was nonetheless persuaded to participate in an oral history. Three interviews were subsequently conducted on June 29, July 6, and July 10, 1995 at the home in Santa Rosa (sixty miles north of San Francisco) which Lewis shares with her partner Shirley. It did not take long for her natural warmth and ebullience to re-emerge, tempered by the tensions and emotionality of her "AIDS years".

Lewis received the lightly edited transcripts and returned them with a few changes. She also donated a real treasure to UCSF Library's AIDS History Project: the diary of Bobbi Campbell, an early AIDS activist and person with AIDS--and Lewis's friend. She also gave the library the bulk of her AIDS-related documents.

This oral history conveys the enormity of the epidemic not so much in terms of its eventual geographic scope but rather in terms of the emotional burden which it placed on those who chose to become involved in its earliest stage. Lewis in concluding remarked about its personal impact: "All of [the AIDS physicians]--all of us--had our lives fundamentally changed." Her greatest contribution? "I think it had to do with connecting people with each other."

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Sally Smith Hughes, Ph.D.
Research Historian and Principal Editor

July 1998
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Carole Angela Lewis

Date of birth 7-19-44 Birthplace Adrian Michigan

Father's full name C. J. Lewis

Occupation Photographer Birthplace Michigan

Mother's full name Carolyn Mae Lewis

Occupation Special Ed Teacher Birthplace Kentucky

Your ~~spouse~~ ^{partner} Shirley A. Kolmware

Occupation Chef-restaurant owner Birthplace New Orleans

Your children 0

Where did you grow up? Clearwater Florida

Present community Santa Rosa, Ca

Education BS - Clearwater High School; Diploma - Charity Hospital School of Nursing; BSN - University of Washington - UCSF

Occupation(s) Retired from nursing 3 1/2 yrs. ago - currently work with Shirley in running our restaurant - Chez Marie

Areas of expertise in the past - Nursing education & administration.

Currently enjoying working at the restaurant & getting to do what I went into nursing for - taking care of people.

Other interests or activities gardening, working on computer reading cookbooks

Organizations in which you are active none at the current time

INTERVIEW WITH ANGIE LEWIS

I FAMILY BACKGROUND, EDUCATION, AND EARLY CAREER

[Interview 1: June 29, 1995] ##¹

Family

Hughes: Angie, tell me a little about your background and education before the epidemic.

Lewis: Before the epidemic, I always knew I wanted to be a nurse, from the very earliest time in my life. My mother [Carolyn Mae Lewis] used to tell a story of me being like three years old at the vacation Bible school, and mopping other kids' noses and taking care of other people. I was really clear from my earliest years that I was going to be a nurse. So I went to a three-year diploma nursing program in New Orleans called Charity [Hospital School of Nursing, 1962-1965].

Hughes: New Orleans is where you were born?

Lewis: No, I was born in Michigan. I was the only child, and my mom was forty-five when I was born.

Hughes: Unusual.

Lewis: Yes, very unusual in 1944. They actually retired when I was five. Mother was fifty. They moved to Florida and had a little apartment building that they ran, and my dad did a few odd jobs. I actually have come to realize my mother was pretty progressive, although I hadn't perceived it at the time. She and my dad had been married in '29, and she was forced to stop her education. She was in occupational therapy school at the time, which was sort

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

of unusual in '29, and she was forced to stop school, because they didn't allow married students.

After I was in grade school--so that was in 1952 or 1953--she went back and finished her baccalaureate, did a master's, and then taught. She was still teaching through most of the sixties. She was ahead of her time in terms of pursuing education as a real mature student.

So I was reared in Florida, as an only child. Because my parents were older, I was reared with a lot of maturity. My mom particularly had a real sort of obsession with making sure I'd be able to take care of myself. I never got an allowance. I remember going to public speaking contests, babysitting, and that was how I would earn money.

Nursing Education and First Jobs

Charity Hospital School of Nursing, New Orleans, 1962-1965

Lewis: I had a state scholarship to University of Florida or Florida State. They gave two in nursing and two in teaching or something of that nature in each county. I won one for nursing. I had talked to the director of nursing at our local hospital, and she said, "Oh, you should go to a diploma program. Don't get your degree. That isn't what you want to do." So I turned down the scholarship and went to the diploma program at Charity Hospital.

There was also a financial piece to it, because for three years at Charity, including room and board and everything, it was \$380 or something. [laughter] It was like nothing. I don't know what the university cost, but it would have been considerably more.

Hughes: What was the difference between the diploma and the degree? Why did you get that advice?

Lewis: I think because she was a real old-school nurse, and wasn't really up on what was happening in terms of the field. It was a wonderful education, although it was an education that I had problems with at times. I finally at one point went over to Tulane and took night classes at the university, because I just felt like I wasn't getting what I wanted.

Hughes: It wasn't academic enough?

Lewis: Yes, right. I knew that I was going to want more education. I had read Cherry Ames and Sue Barton and all those nursing books, and I knew I wanted to be in a big city hospital. I wanted to be right in the middle of the action. And Charity was one of the places. Grady [Hospital in Atlanta] would have been another one, and Bellevue [Hospital] in New York was another one I was really intrigued with. But I didn't want to go so far away from home, and neither of my folks wanted me to go so far away from home.

So I lived in New Orleans for three years while I went to school, and that was when I met Shirley [Palmisano]. Charity was where you lived in a dorm. I think we were allowed to move out into an apartment the last six months or something--very restrictive, a Catholic program. So I spent three years there.

Staff Nurse, Surgical Unit, Veterans Administration Hospital,
New Orleans, 1965-1966

Lewis: My very first job was at the VA there in New Orleans. I was there for about six months, and Shirl and I were living in the city. But my father had what at the time they thought might be some cancer, and so we came back to Florida, and we lived there for the next five years. It didn't turn out that [cancer] was what was happening, but we thought it was.

Staff Nurse and Head Nurse, Perinatal Unit, Mease Hospital
and Clinic, Dunedin, Florida, 1966-1970

Lewis: When I went to Florida, I went to a real small hospital called Mease Hospital. I was hired originally as a night nurse. It was only maybe 100 beds; it was very small. And I became a rising star there. I was young; I had graduated from this very well-known hospital; the director liked me. I never had an official title of assistant director of nursing, but I sort of had that role in lots of ways. I became the director of education, and did a lot of educational kinds of things.

That was where I first started to get an awareness of education and enjoyed that role, which was a very big part of what I did with HIV. I stayed in that little hospital for five years.

Through that time, I realized that I really wanted and needed to get my nursing degree. So I corresponded with some nurses in

Seattle whom I really admired who were faculty members at the University of Washington. It was during this time that I first met a nurse who had a master's, and I was like, "Ah!" And then I met somebody with a doctorate! I was like, "Wow!" Because we were in a little area in Florida where there weren't many resources. There was a junior college where they had an AA [Associate of Arts] program, and I did go to a couple workshops, but basically, we were sort of insular. So Shirley and I started looking around.

During this time, I wasn't really thinking about coming out; I was very closeted through these years. I mean, to the point when I answered my phone at home, if someone asked for Angie, I knew they were safe, and if somebody asked for Carole, which was the name I went by at work, I had a different persona. But I was beginning to come to grips with that a little bit, so I was in therapy for six or eight months, not too long before we moved.

Staff Nurse and Assistant Head Nurse, Perinatal Unit,
University of Washington, 1970-1971

Lewis: One of the things I discussed with the therapist was where we were going to move, because where we lived in Florida, there was not one place where I could get a degree, even a baccalaureate, in nursing, within like a 200 or 300 mile radius. You had to either go up to Tallahassee or to Gainesville, or there may have been something down in Miami. But we were like right in the middle of the state. Now there is a university at Tampa that's quite well known and well regarded, but that hadn't been started then.

So we knew we were going to move, and it was like, "Well, if we're going to have to pack up and sell our house and move, we can move anywhere. We're footloose and fancy-free." So the therapist talked a lot about Seattle, and it being a very open and accepting city. And it fit in. I had talked with this woman that I met who came as a consultant to where I worked. She had been in education on the East Coast. I remember asking her one day in the car, "Now, if you could go anywhere for a nursing degree, where would you go?" And she named UW [University of Washington], UCSF [University of California, San Francisco], Case Western, and there may have been one other one. Case Western was private, very expensive. I knew that if I went to Seattle, that I could wait a year and become a resident, get my degree for not so much money. I don't remember why we didn't go to San Francisco at that point, except that I had it in my mind that I didn't want both degrees from the same institution.

So anyway, we moved to Seattle and lived there from 1970 to 1973. I loved Seattle. During that time, we both completed our baccalaureate degrees at the University of Washington. Shirley's degree is in education and psychology. It was in Seattle that I went from outright lying about my sexual orientation to not saying anything. There was a certain set of colleagues that I was honest with, but generally in my work situation I wasn't. I just didn't say anything. But when I had been in Florida, I had been making up stories, creating a second, artificial life.

Hughes: Was that your evolution, or was it a more favorable setting in Seattle?

Lewis: Partially it was just being in the environment of Florida. There were some women in our restaurant the other day who were from Florida, and they were saying how it's still really tough there, and that most people remain very closeted. That's just part of that environment. But I knew that to actualize myself, for us to be able to grow in the way we wanted to grow, we needed to be somewhere where we could be clear about who we were.

At the university, I began to meet nursing colleagues who were of a very different caliber than anyone I had ever met before, and I really enjoyed that period. My time getting my baccalaureate, when I look back on my career, was one of the richest times of both my personal and professional growth. I really loved the intellectual stimulation of that time.

When I first had gone to that little hospital in Florida, they had hired me as the OB [obstetrics] head nurse. I guess I started as a night nurse, and then after about six weeks or eight weeks, the director said, "You're going to be the new head nurse for the OB unit." And I was like, "OB? I don't like OB. I don't want to do that." She said, "You work here. You're doing it. I want you to do it." So I did that until I became the director of education. So I'd had an OB background, although in a very small hospital.

When I went to the University Hospital at University of Washington, I took a position as the Obstetrical Charge Nurse on evenings, because I could do that and still go to school during the day. So I did that for almost three years. When we went to Seattle, we went with very little preparation. We didn't realize there was a Boeing strike on, and that every woman who was a nurse whose husband was a laid-off Boeing engineer was doing her best to support her family working as a nurse. So there were very few nursing jobs. I had always thought, I'm a nurse; I can always work.

Hughes: And that wasn't the case.

Lewis: It was really a real startling thing to me to get there and realize that I couldn't just walk in and say, "Hey, I want to work." So I ended up working on a post-cardiac unit, which I had never had any experience or much knowledge in, but I only did that for six months. I put in an application to the university as soon as I arrived in town, and after a few months, I was offered a position on the OB unit. It just took a little while. It also was key in terms of my education, because as a UW employee, I got a break in my tuition.

Nursing Care Coordinator, Perinatal Unit, Alta Bates
Hospital, Berkeley, 1973-1975

Lewis: As soon as I graduated, though, I knew I wanted to get to San Francisco. San Francisco was where it was happening, and I wanted to be there. So I remember we rented a truck and we packed and moved the day after graduation, or the night of graduation. I was like, "I want to get out of here."

Hughes: Now, you were thinking not so much in terms of nursing, but of a more accepting climate?

Lewis: Right. It had more to do with that. I didn't have a job in mind.

We had a good friend, D.G., a man, that we had known in Florida who had moved out here. We used to sit on the beach in Florida and talk about what it would be like to live in San Francisco. He got to San Francisco before we did. When I was at the 1981 BAPHR [Bay Area Physicians for Human Rights] conference and heard about this disease that was going to kill gay men who were promiscuous, he was one of the three people I thought of, and he in fact did die within a reasonably short period of time. D.G. was one of the first patients that Cliff Morrison helped take care of.

So we moved to San Francisco, and I began to apply for jobs. The first place I remember applying was San Francisco General, and I very much wanted to work there--the first time I walked in, it felt like home; I guess because it reminded me of Charity Hospital where I had trained. My initial interview went well, and they had a job open for the OB head nurse, but I soon learned the reality of civil service system at SFGH. I couldn't seem to get any information from them until several weeks later, when I received a postcard saying I was eligible to sit for the exam for the position, and that I would be notified in several months when the exam would be scheduled. By the time I got the postcard, I

already had taken a position as OB Nursing Care Coordinator [NCC] at Alta Bates Hospital in Berkeley. I remained the NCC for a couple of years [1973-1975]. That was the first time since I left Florida that I had been in the private sector. It just became real clear to me I didn't like the private sector at all.
[laughs]

Hughes: Why?

Lewis: Well, the controllingness of the physicians was one of the major points. Their sense that they were the be-all and the end-all. There were a couple of instances when I really knocked heads with physicians in my role as the patient advocate, one instance in particular having to do with sterilization of a young woman, and a doctor who wanted to do it. It was ethically unconscionable. It was not appropriate, and I stopped him. It didn't make him happy.

Graduate Student, School of Nursing, UCSF, 1976-1979; Head Nurse, Perinatal Unit, Moffitt Hospital, 1975-1980

Lewis: I became increasingly unhappy at Alta Bates, so I started looking around. I put in an application to UCSF [University of California, San Francisco], and was hired as the head nurse of their OB unit up on floor 15 in Moffitt [Hospital]. I was there in that position for about five years [1975-1980].

Now, during those years, I did a lot of growing in terms of coming out, because that was a period of time when I went back and got my master's in perinatal nursing. I went to school part-time and worked full-time. I was able to do both, right there at UC. One of the things I did was take a minor in human sexuality, which was a program that was pretty short-lived. I think there were only two or three groups of nursing students that got to take the program, and then they ran out of funds. I think there were twelve of us in the master's nursing program who took that sequence of courses. There were only four courses in the subject, I think, over three years.

Lecturing on Human Sexuality

Lewis: The human sexuality program was very helpful to me in terms of coming to grips with being a lesbian and coming out and simply becoming comfortable with sexuality. It was also very helpful,

because when I got into AIDS education, I had had experience and some education relative to human sexuality, which a lot of people didn't have. Also, the faculty member [Tony Ayres, R.N., M.A.] who did the human sexuality program and courses asked me if I would do the lecture on gay and lesbian sexuality.

I did that for a number of years, until they phased out human sexuality in the curriculum. I think having had that experience of getting up in front of a group and talking about sexual things, and about my sexuality personally, made it easier for me when the time came to start doing public speaking on AIDS. Also, I had already come out publicly in those controlled situations. It was another big jump to come out in the much less controlled situation of a public lecture on AIDS.

I would always try to make a point at some time in every lecture or class or whatever that I was giving of saying, "Those of us who are members of the lesbian and gay community," being inclusive of myself. Sometimes at the beginning, more often in the middle or the end of a talk, I would somehow get that in.

Hughes: Did you get any reaction when you said that?

Lewis: I think I protected myself from that by virtue of doing it more toward the middle or the end of the talk. You establish a rapport with an audience, and you nurse them along and get them to where they're empathetic to you and to your case, and then I think you can say things like that, that people don't find offensive in the same way they might if you walked in and said, "Yes, I'm the lesbian for today."

Nurse Educator and Clinical Nurse, Moffitt-Long Hospital,
UCSF, 1980-1986

Lewis: In about 1980, I had an accident which resulted in knee surgery, and I was out of work, on disability, for about seven months--a long period of time. During that time, I left my OB position, because they couldn't hold a head nurse job for months and months waiting for me. So when I came back, I came back in nursing education and research.

Hughes: Which was your choice?

Lewis: Yes, I wanted to do that. It was a good move for me personally, because I really was enjoying the role of educator.

II THE AIDS EPIDEMIC

Workshop on Human Sexuality, UCSF

Lewis: Now, it was in that role as Nurse Educator in Nursing Education and Research [E&R] that some time in the latter part of 1980 or beginning of '81, I had coordinated a workshop on human sexuality, particularly focused on gay male sexuality.

Hughes: At UCSF?

Lewis: At UC, right. Budgets were a lot more flush than they are now; we had a lot of leeway to suggest programs that we were interested in, and do them. I think some gay male nurses asked me to do that workshop. I don't remember quite how it evolved. But I took it on and coordinated the program. I had the reputation of being the woman, the gay woman, the lesbian, who was interested in sexuality. I don't remember if I even came out at this conference. But none of the other nurse educators had ever, to the best of my knowledge, presented any kind of program that was sexually oriented, so I had sort of broken a taboo and was looked upon as a little bit weird. [laughter]

The BAPHR Conference, June 1981

Format

Lewis: As a result of coordinating the E&R program on gay male sexuality, I became aware of a program that BAPHR was going to put on during the 1981 Gay Freedom Day weekend. I thought, "I'd really like to go to that." So I called and talked to the physician who had done a presentation for us at UC and said that I'd like to go to the

conference. He said, "Okay." I also had a gay male physician friend from Marin County who was going to go, so I went with him. It was I think a two-day conference. It may have just been one day; I don't remember precisely.

Hughes: On gay and lesbian health?

Lewis: Yes, the whole event was on gay and lesbian health. A lot of it was done by therapists, on psychological aspects, and then there were segments that were very physiologic-based, about STDs [sexually transmitted diseases] and prostate cancer--all kinds of different things. It was mostly focused on men, because 90 percent of the people at the conference, maybe even 95 percent, were men. As far as I know, I was the only nurse present, although there may have been others I was unaware of.

Presentation on Gay Male Sexuality

Lewis: Actually, there were things I learned from several presentations at the BAPHR conference that I used later in AIDS education. There was one presentation I remember by a psychologist in L.A. who had done a study of 500 male couples, and there was a book from this called The Male Couple, and it was the author who was speaking. He was saying that of the 500 couples that he had interviewed, who had quite a wide range of age and years together as partners, but I think they had to have been together five years or more, he found not one couple that had been monogamous. Gay male sexuality, even in coupled individuals, involved other people, and many of those couples did that very consciously and knowingly between themselves.

That was really helpful and important information for me to realize, because in my experience as a lesbian, things had been quite different. As we got into the epidemic, especially in the very early years, we heard so much about promiscuity, and this information helped me relate on a more real level with people, with gay men particularly, about their sexual behavior. Things have changed in many gay male couples now and there is a lot of monogamy. But in those days, apparently there wasn't.

And I hadn't really been consciously aware of that. I knew that some of our friends were very promiscuous, and they would come and stay at our house and go to the baths, but I just didn't think that much about it. It was just the way things were.

Hughes: You were becoming more conscious because, as a nurse, it occurred to you, Well, here is a lot of exposure to disease?

Lewis: Yes. As I learned more about how gay men related to each other sexually, both those who were single and those who were coupled, and as I gained awareness of specific sexual practices, it became increasingly clear that many sexual practices of gay men were dangerous to one's health. Of course, as all of gay San Francisco could have told you at the time, advising individuals to curtail their sexual practices raised many red flags related to civil liberties and the issue was definitely a topic of hot debate.

Alvin Friedman-Kien's Presentation on Kaposi's Sarcoma

Lewis: The BAPHR conference, which was either right after the first MMWR [Morbidity and Mortality Weekly Report] on the epidemic, or just before it, was probably in the third week of June of 1981.

Hughes: If that's the case, then it was between the first two reports on AIDS in the MMWR.¹

Lewis: Yes. I remember that at the conference, Friedman-Kien gave the closing address and said, even at the get-go, that the men who were getting this disease were sexually promiscuous, and that there was some connectedness there that he was unable to define between sexual promiscuity and the disease.

Hughes: He was taking a sexual history at that point?

Lewis: Apparently he must have been. There were a very limited number of cases, and I don't know how he had come to this conclusion.

Hughes: Now, would taking a sexual history be common procedure?

Lewis: No. It's not common procedure now, much less ten years ago.

Hughes: And he's a dermatologist, so it would be even less so. I can imagine for somebody specializing in STDs [sexually transmitted diseases] that might be a natural way to go, but not in dermatology.

¹ Pneumocystis pneumonia--Los Angeles. MMWR 1981, 30:250-252 (June 5, 1981); Kaposi's sarcoma and Pneumocystis pneumonia among homosexual men --New York City and California. MMWR 1981, 30:305-307 (July 3, 1981).

Lewis: Right, it makes perfect sense. I think he came to that conclusion only because he was a member of the gay community, and here he had these gay men who were getting this disease, and he was looking for common threads, I'm guessing.

I had never heard of Kaposi's sarcoma [KS]. That was a totally new term to me.

Hughes: Did Friedman-Kien mention any other conditions that later become part of the syndrome?

Lewis: PCP [Pneumocystis carinii pneumonia].

Hughes: Or other opportunistic infections?

Lewis: No, I don't think so. I don't remember that clearly to be able to say absolutely, but I don't believe so. But he as a dermatologist was clearly most focused on the KS, and that was what his presentation was about. It was a fairly short presentation, maybe twenty minutes or so.

Hughes: Did people take note?

Lewis: Oh, the whole room was just like awestruck. We were in a conference on gay and lesbian health, and here was something being described that was killing gay men, and nobody knew about it. It was totally frightening, because almost everybody in the audience was a gay man, and therefore themselves vulnerable. I mean, the whole audience was just riveted. Nobody moved. They could see themselves in the situation, as well as those they loved and cared for. I remember it as a really pivotal experience.

Hughes: Did you think that somebody should do something about this in San Francisco?

Lewis: Yes. I remember I was very concerned about three of our friends who were very sexually active. Shirley had driven me over, and she picked me up at the end of the day. I remember getting in the car and the first thing I said was, "I just heard about this disease that's killing gay men who are sexually promiscuous. We know people who are going to be really at risk if this is real." I had a sense that it was real, but at the same time, it was like, "Well, maybe this isn't anything that's really going to pan out." So I didn't really do anything at that point. I didn't know them at the time, but Marcus Conant and Friedman-Kien were good friends, and Marcus had been the person who invited Friedman-Kien and did the introduction. Conant may have spoken earlier in the program on other dermatology things; I don't remember.

Hughes: You don't have that program?

Lewis: No. It wasn't something I saved because I didn't realize its future significance. And I don't even know that Friedman-Kien's talk was on the program. I think it was an add-on kind of thing-- The feeling was: this is something that's happening right now and you need to hear about it. It's not on the program because we didn't know about it when we made the program up, but we've been able to bring this man here, and he will tell you what little we do know.

I didn't do anything specifically about it, except to be aware of it and to start watching the rounds that were listed in the UCSF Newsbreak.

Hughes: You didn't see the MMWR on KS that came out in early July?

Lewis: No, I had never seen the MMWR. As a nurse educator, it just wasn't something that I read. Our infectious disease nurses saw it, I'm sure, on a regular basis. It became very much a part of what I was aware of later, but at that point in time, I may have heard of the MMWR as something that certain epidemiologists keep track of, but it wasn't anything I read.

Marcus Conant's Rounds on Kaposi's Sarcoma, UCSF

Lewis: So I just watched out, and it was very shortly after that BAPHR conference that Marc Conant put on the first rounds on KS at UC. I don't know if it was in medicine or in dermatology. I really am not clear which venue he was using, because he was a member, I think, of both departments.¹ But I saw it advertised, and I immediately made plans and went to see it.

Hughes: Did he present cases at rounds?

Lewis: Yes, I think he did, and I know he had slides. It was a formal presentation, as one does at rounds.

Hughes: What was the response?

Lewis: I think it was scientific interest. I don't necessarily remember whether the audience was particularly gay-focused. There are an

¹ Conant's only departmental affiliation at UCSF has been with the Department of Dermatology.

awful lot of physicians at UC who are gay, but certainly, the majority are heterosexual. I don't remember the audience composition.

Hughes: Do physicians come to rounds in their specialty regardless of the topic, or would this have been a selected audience, those that might be interested in sexual or gay diseases?

Lewis: One of the keys would be to know what the title was. If it was Kaposi's sarcoma just flat out, that would be different than a title, "Kaposi's sarcoma and gay men," and I have no way of knowing how it was advertised. But that was one of the things that you did as an educator: look at your title and what audience you might attract. The very first major conference we did was called, "Kaposi's sarcoma and Pneumocystis pneumonia: New Phenomena Among Gay Men." That's the kind of title that attracts gay nurses.

Hughes: Which was deliberate on your part?

Lewis: Yes, right. It's a way of educating them, disseminating the information to the community that needs it. And it also lets people know that there is going to be discussion of issues that might be potentially sensitive, like issues around sexuality.

Hughes: Do you remember if the KS Clinic was up and running by the time of Conant's rounds?¹

Lewis: Yes, it was.

The KS Study Group

Lewis: After rounds were over, I went up and introduced myself to Marc Conant, which was the first time I had ever met him. I just said something like, "Dr. Conant, I'm a nurse educator here at UC. I'm also a lesbian, and I'm really interested and concerned about these men who are sick. If there's ever anything I can do, I would like to be helpful."

¹ The KS Clinic first met on September 21, 1981. (Conant to William Epstein et al., September 2, 1981. Conant's Kaposi's Sarcoma Notebook, 1981-2/1982. Hereafter, KSN.)

He said, "Oh, well, I'm doing a KS Study Group every Thursday morning at nine o'clock over in dermatology.¹ Why don't you come to that?" I said, "Oh, I'd very much like to do that." So I did that, and the first one that I went to, there were maybe eight people in a circle, sitting in chairs. And because I was new to the group, I was asked to introduce myself, so I did my little shtick.

That was the first time I had ever seen or met Paul Volberding or Don Abrams or Connie Wofsy or any of that group.

Hughes: They were all there?

Lewis: Yes, they were attending the meeting regularly, as was Selma Dritz, I think.

Hughes: Altman?

Lewis: Dave Altman? Off and on, but not with regularity. [James] Groundwater was always really involved. He had to come from his private office to do it, which was a pretty big burden, but he did it on a really faithful basis.

Within a year, or less probably, the room was filled with forty people or more. It was very different as things grew. But at that very first one that I went to, it was just a little group sitting in the derm conference room.

Bobbi Campbell

Patient Presentations

Hughes: Was there a patient presentation?

Lewis: I don't know if there was one that very first time I went or not. Now, Conant did do patient presentations; he would sometimes have patients come in.

I met Bobbi Campbell as a result of one of these conferences.

¹ The KS Clinic was held on Thursdays from 9:00 to 11:00 a.m., followed by the study group from 11:00 to 12:00. (Conant to Corrina Kaarlela, October 1, 1981. KSN 1981-2/1982.)

Hughes: Because he was presented?

Lewis: Yes, right, and I was there when he was presented. And that really was a galvanizing thing for me, because I was struck by the inhumanity of the presentation.

Hughes: Which was by Dr. Conant?

Lewis: Yes. But it wasn't that he was mean or cruel; it was just that he was so very scientific. We all trouped in, and it was like, "Touch this, and feel this lesion, and see this." I think they had already said that the patient was a nurse. I remember hanging back, because I didn't feel it was necessary for me to touch him in this physical way.

After Marc and the docs had gone out, I introduced myself to Bobbi. I said, "I'm a nurse educator here, and if there's ever anything I can do, I'd be happy to do that." We connected briefly, and then I went back to the meeting.

Hughes: Had Bobbi himself reacted to this treatment?

Lewis: No, I think that was the way he expected it would be. There was nothing really offensive about it.

Hughes: Well, it was the usual routine.

Lewis: Yes, that was how physicians do it. They are there to present their case and give their evidence, and then discuss it among themselves. The person who is living the experience is a third party. Physicians often talk about patients in their presence in the third person.

Hughes: Yes, almost as though they don't exist, except as a demonstration.

Lewis: Yes, exactly. And there was nothing unusual about it, but as a nurse, it was something that in my experience I had not seen that much. Although I had been a nurse for years at that point, I had not personalized the experience of the distancing that occurred between the patient and the provider during rounds. So it was really hard for me to realize that this human being was going through all that he must be going through, and so I connected with Bobbi.

Introduction

Lewis: I originally met Bobbi in the School of Nursing coffee room, when I was introduced to him by Tony Ayres R.N., Ph.D. Toni was my instructor for Human Sexuality and Bobbi had given guest lectures for her on homosexuality. She mentioned that Bobbi had been sick, and out of earshot she may have mentioned the possibility of KS. I do remember that when she introduced him to me he had not yet been diagnosed. When I later saw Bobbi with Marcus, it was the second time I had met him, the time in the cafeteria being the first. As I recall, It was some time after Marc had started his rounds that Bobbi was diagnosed with Kaposi's sarcoma.¹

Implications of a KS Diagnosis

Hughes: What did it mean, to be diagnosed with KS at that stage?

Lewis: It meant that you were going to die. It meant that you had a disease that no one understood, and no one could tell you how you got it, how you passed it, or if you could hurt anybody. It meant that you would be exposed as a gay person, a gay man particularly. It meant that one better start getting one's affairs in order, so that meant dealing with family, if it hadn't been dealt with before. Those are the major things, I think, that come to my mind, that I was very aware of. And death was very much a part of it from the get-go.

Fear of Infection

Hughes: What about fear, on both sides?

Lewis: Oh, yes, absolutely. Because you didn't know--there was so much grey. When I used to give classes, I would talk about dealing with greys. We want absolutes; we want black and white; we want to know, but we don't know. And not knowing is so hard, and it's very scary, and we all feel very vulnerable.

I remember very clearly, Shirley and I were living in Woodacre [in Marin County] during the first few months of this whole thing. I was already going to see patients on a regular

¹ Campbell was diagnosed with KS in October, 1981. (Richard Saltus. New Reports on Epidemic among Gay Men. San Francisco Examiner, December 10, 1981, p. B7.)

basis. I woke up one night in the middle of the night drenched in sweat and very sick. I had the flu or something. I was convinced, absolutely, totally convinced, this was IT. Whatever AIDS is, I've got it. I didn't know how you got IT, but, whatever IT was, I'd found the way. And we were both very frightened. I was better in twenty-four hours or something. But it was frightening to think, IT's happened. I'll be the first case of AIDS in health care providers.

Hughes: Was that the first year?

Lewis: Oh, yes, definitely. It was within probably the first five or six months.

The other thing that particular experience did for us was that I had been at that point in time trying to inseminate to get pregnant. With that experience, we had a conversation, and Shirley said, "You could pass this on to the baby. We don't know what it means. You can either try to get pregnant or you can do AIDS work, but you can't do both." So I made a conscious decision to stop inseminating and to keep working in the epidemic.

Hughes: It was the epidemic that was your rationale for giving up insemination?

Lewis: Oh, absolutely.

Although, as I look back on it, the reality was, at that point in time, I didn't have a lot of direct contact with patients, except those I was visiting at Moffitt Hospital. I would see Simón Guzman, and there were a couple of other patients I was seeing by then. I was going to rounds and seeing presentations there. And as I developed programs, I always included patients in the planning, but they were well enough to attend meetings. Basically, there weren't other situations where I was directly involved with patients who were ill.

Hughes: You chose the epidemic instead of insemination?

Lewis: Yes, although, I think, at the time, I had no idea it would go on forever. It was like, well, I'll stop inseminating now for a couple of years, and the epidemic will get resolved, and then I'll do this insemination. I didn't realize I was going to miss out on it for the rest of my life. It was like, this is a decision right now. It feels really important to me to be doing this AIDS work. The AIDS Foundation was just getting started, and I wanted to be part of that.

Perceiving AIDS as a Syndrome

Hughes: Most of the presentations you attended were centered on KS. When and why did you become aware that this disease was really a syndrome, that there was much more to it than skin lesions?

Lewis: It wasn't long at all. In fact, I think the second patient that I became involved with was a guy in the ICU [intensive care unit] who had PCP. He may have had some KS lesions, but it was really PCP that was the issue for him, and that's what he died of. So PCP as an entity was part and parcel of it from the beginning, although I don't remember whether Friedman-Kien talked about it at the BAPHR meeting. But by the time I heard the Marcus Conant talk, he was already talking about both.

Hughes: And other opportunistic infections?

Lewis: Not too much at that point. Now, Bobbi Campbell had had a very bad bout of herpes simplex, and he had bad scarring on his face. I remember him telling me when I first met him that the scarring was from his herpes. He'd been hospitalized for it, and he said that they felt that it was all related to this same syndrome.

Hughes: Which, time-wise, would have made sense?

Lewis: Yes. It fit. Because the immune system was depressed, then it was rational that they could get all kinds of diseases.

Hughes: How soon was the correlation with immune suppression made?

Lewis: Reasonably early. There was a realization that there was a connectedness. I don't know that scientists had established a cause and effect, but in the scientific community that was following this, there was, from the earliest, discussion of suppression of the immune system. So that realization was in my recollection quite early, but certainly not in all its depth and details.

Hughes: I suppose it would be only oncologists or dermatologists who would have had the background to know that until the epidemic, Kaposi's in this country had been seen mainly in people receiving immune suppressive therapy.

Lewis: Yes, it was definitely dermatologists, and then oncologists secondarily, who were aware of that. When you would go to a presentation on KS, the first thing you would get was a little litany about non-AIDS-associated KS, that it strikes sixty- or seventy-year-old Mediterranean males, et cetera. You got that in

the first five minutes of any presentation, because nobody knew anything about this disease, so they had to give everybody a little background to let them know how rare it was, and how it didn't kill people, and how it was traditionally an indolent kind of thing. And then they would move on to what was happening currently.

Hughes: And make the contrast: that the new type of KS occurred in young men; it was much more aggressive, et cetera, et cetera.

AIDS and Ethnicity

Lewis: Young men, and all backgrounds. There wasn't a certain race piece to it. And it was real easy to see the contrast.

Hughes: I hadn't thought of the racial aspect. Is there a tie-in later when the risk groups are created? Remember that Haitians were a risk group? I wonder if that was historical, the fact that KS as originally known did seem to have an ethnic connection.

Lewis: Yes, it was elderly Jewish and Italian men.

Hughes: So I wonder if that somewhat oriented people's thinking about AIDS towards looking for a genetic connection?

Lewis: I don't know. I don't remember much discussion about that. It was just sort of part of the litany. I don't remember them talking about the ethnicity of the gay men who were getting the diseases, except to say that they weren't necessarily Jewish or Italian, that they could be from any ethnic background.

Hughes: Well, and from early on, you had Simón Guzman, an Hispanic man, as an AIDS patient.

Lewis: Yes, Mexican. And black men, and all kinds of men. So yes, I didn't ever have a sense of an ethnic connectedness there.

Press Coverage of the Epidemic

Hughes: I'm interested in how different groups perceive what later becomes AIDS. The gay and straight press begin to talk about gay plague, gay cancer. They're focusing, I believe, on the KS part of the syndrome, are they not?

Lewis: Yes, pretty much. [tape interruption] Do you know about when that was? I remember that there were certainly cover stories--

Hughes: By 1982, maybe earlier than that, the terms were in use.¹ There's not too much attention given to the epidemic beyond a small group within the medical and gay communities until 1982.

Lewis: Right, that would be my memory. I can remember feeling, Nobody in the world knows or cares about this epidemic.

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Lewis: There was not that much in the local press in that first year.

Hughes: Even in the gay press?

Lewis: No, the gay press had plenty. I'm talking about the Chronicle and the Examiner and that kind of publication.

Hughes: The gay press mentioned both KS and PCP?

Lewis: Yes. Pretty much. They would have health-related articles in the BAR [Bay Area Reporter] and whatever the gay press was then.

Hughes: The Sentinel?

Lewis: Sentinel, right. They would have occasional articles that were done by guest physicians in a health perspective, and there would sometimes be one that was just on KS. But you would rarely ever have one on just Pneumocystis. If it was going to be on Pneumocystis, it would also include discussion of KS.

Hughes: Why?

Lewis: At this point, only gay men were being identified in the epidemic. I was going to say that it might have been because KS was identified as the gay man's disease, where Pneumocystis was something that other people got. But there weren't many other people in the epidemic at that point.

¹ The term "gay cancer" was used in an article appearing in New York Native, a gay newspaper, in July, 1981. (Lawrence Mass, M.D., Cancer in the Gay Community. New York Native, issue 17, July 27-August 9, 1981.) For a history of the press's role in the AIDS epidemic, see: James Kinsella. Covering the Plague: AIDS in the American Media. New Brunswick: Rutgers University Press, 1989.

Access to Information about AIDS

Lewis: There were thousands and thousands and thousands of gay men who had never heard of any of this. Unless you picked up the right papers at the right time, and read the right articles, you could be living your life and have no idea that there was anything like this around--just like a lot of people today, particularly people outside the gay community, who just have no awareness that this disease could affect them.

Hughes: I'm thinking of your description of the audience's reaction when they heard Friedman-Kien's presentation, where everybody in that room thought, Here is something that directly impacts my life.

Lewis: Right.

Hughes: And yet you're saying that that feeling--

Lewis: Did not pervade the gay community.

Hughes: Why not?

Lewis: Well, I think there are a lot of reasons. None of us like to think about our own death. Certainly those who are outside the medical realm can go through their lives not thinking about it, period, as can many in the medical environment. So I think that's a big piece. It's too scary; we don't want to think about it, that kind of thing. And there are a lot of people who don't read the gay press.

Hughes: A lot of people in the gay community?

Lewis: Oh, yes. If you happen to live on Castro [Street] or right down in the center of the Castro District, the papers are right there. But if you live in Marin or out in the Avenues [in San Francisco] or whatever, you don't necessarily even have access to the gay press. You mostly could only get it on Castro.

Hughes: You can't subscribe?

Lewis: I don't know if you could or not at that point.

Hughes: But it was more, you see it in the stand and you pick it up?

Lewis: Definitely. That's the way the gay papers have always been, even to this day. You don't get a subscription.

Hughes: That's important in terms of getting the information out, because obviously only a select group sees the papers.

Lewis: And you have to get there when the papers are there. They only make so many copies. I can remember a few times when we wanted to get copies, and you'd have to get down there early, and not quite wait in line but damn close, to make certain that you got a copy. So that was another piece of it.

I think people feel a certain invulnerability, especially young people, like this disease doesn't affect me. The publicity about the disease was very much the kind where it was easy to say, "That isn't me. I'm not promiscuous." Promiscuity, especially, was a piece where people could easily say, "Well, I'm not. Promiscuous is more than I do." If you have 300 partners a year, you can think you're not promiscuous if you know somebody who has 500. So it's all relative, and it was easy to feel that that isn't me.

The Epidemic's Potential Enormity

Lewis: I think for those physicians who were at that conference and heard Friedman-Kien, there was a sense of personal vulnerability, but there also was a sense of the potential enormity of what this could mean, if what he was saying was right.

Hughes: You mean, knowing what physicians knew about how diseases are communicated?

Lewis: About gay men. Well, they knew their patients. Most of the people in that room had a large percentage, more than 50 percent, of gay men among their patients. They knew those men, both personally and professionally. So they knew that a lot of men are promiscuous, and that if, in fact, this were a sexually transmitted disease, that there was an enormous number of men who were at risk. So I think part of it was a sense of their own potential vulnerability, but there was also just a sense of, Wow, this disease could be really terrible.

Hughes: And is that what you were thinking too?

Lewis: Oh, yes. This presentation we'd heard just earlier that day or the day before about these 500 male couples, not a single one had been monogamous. I mean, that just illustrated to me in a more concrete way the enormity of the problem and the potential disaster.

Pneumocystis Pneumonia

- Hughes: Most people, if they find something weird on their skin, are going to take immediate notice. But would PCP grab a person's attention?
- Lewis: It wouldn't necessarily, except it could become very severe very quickly, and these people died really fast.
- Hughes: In its early stages, a person might think, Well, maybe I have a bad cold, and he'd just let it go for a bit?
- Lewis: Right.
- Hughes: When would a person with PCP become alarmed enough to say, "I'd better take myself to my physician and see what's going on here"?
- Lewis: Difficulty breathing is the key point. It would come on quite suddenly, and it would be quite severe.
- Hughes: So you wouldn't miss it.
- Lewis: You wouldn't miss it. And these men would most often end up in ICU [intensive care unit] at that time.
- Hughes: How would they get there?
- Lewis: They would mostly go to ER [emergency room].
- Hughes: So it would be that bad.
- Lewis: Yes. They would get themselves, or a family member or a lover, whomever, would get them to the ER, because they were having trouble breathing.
- Hughes: It wouldn't be a gradual worsening?
- Lewis: It wasn't slow. It was sudden.
- Hughes: So it was less a referral through a community physician; it was more a direct route to the emergency room?
- Lewis: Right.
- Hughes: And then from there, probably to the ICU?

Lewis: Most often to the ICU in those days. Now, they don't go to the ICU so often. They're even treating PCP outpatient now. Things have really changed very dramatically.

Places at UCSF where AIDS Patients Might Present

Hughes: I'm so aware of the KS Clinic, but there were other places where people with this syndrome must have presented themselves, because not everybody came with a KS lesion, or even if they had a KS lesion, that might not have been their primary complaint.

Lewis: The lesion could be internal.

Hughes: Yes. Where are the places at UCSF that they could have gone?

Lewis: In the early days, the places that they would have gone would have been to the dermatology clinic, if it was a skin lesion, in which case they generally would have been referred to Marc.

Hughes: In the KS Clinic?

Lewis: No, there was no KS Clinic; it was the derm clinic, dermatology just generally. Helen [Schietinger] helped start the KS Clinic, and that didn't happen until probably--

Hughes: Helen began as nurse coordinator on January 1, 1982. But the KS Clinic precedes her arrival by three months. The KS Clinic saw its first patient on September 21, 1981.

Did people, did the world out there, know it was the KS Clinic, or was it just a dermatology clinic?

Lewis: Yes, it was a dermatology clinic. They didn't have any notion that there was something that had been brought together to try to deal with this [disease], because we didn't know what "this" was, we didn't know anything. The patients started coming because the dermatologists, either in the community like Jim Groundwater, or Marc Conant, were seeing these lesions and trying to deal with them, and they were in young gay men. So the way people would get care would be through either Marc and the KS Clinic, or the private physicians.

The Role of Private Physicians

Lewis: Private physicians usually cared for those patients within their practice and at whatever hospital they were affiliated with.

Hughes: Now, this is early on?

Lewis: Yes. Like Jim Groundwater. He wasn't a UC physician. I forget where his patients were. Bob [Robert] Bolan was at Presbyterian [Hospital], I think. There were three or four physicians who were well known as gay providers.

Hughes: You said Dr. Groundwater came to the KS Study Group.

Lewis: Right, he came. And I think Bolan did very early on, too.

Hughes: So they were up-to-date, they knew whatever--

Lewis: As much as anybody knew. There wasn't a lot known at that point in time.

Hughes: So they wouldn't refer their patients to the KS Clinic?

Lewis: Not as an absolute thing, no. They wanted to manage their own patients.

Hughes: They might have referred patients to the KS Clinic, not so much for the patient's sake, but because it was where research was going on on this disease.

Lewis: That's true. And they might refer a patient to a certain study, but still maintain his care in the private sector.

Patients very often have a private physician and still participate in research. One does not negate the other. In some circumstances, it does. There are some research protocols that are so intensive that you don't need a private physician; it's a waste of money and time. But at that point in time, the patients kept their private physician and still might be in Helen's studies and working with her.

Hughes: Which would be an occasional thing, right?

Lewis: Yes.

Hughes: I understand that the KS Clinic was not set up to give ongoing care.

Lewis: Right.

Hughes: A patient came in to have blood drawn, and maybe a biopsy done, and that sort of thing?

Lewis: It wasn't where you went for primary care. You went for primary care to your private physician.

Hughes: And the patients were aware of the distinction?

Lewis: They became aware of it pretty quick. Think about how expensive that is. The studies were covered if they had funding for them, but sometimes they didn't.

Health Insurance

Lewis: Insurance issues were a big question in all of this, because at the beginning, insurance carriers didn't know what it meant to have KS, or to have PCP. But very quickly, especially once T cells started getting counted and there were markers for the disease, insurance carriers looked out for young men who had these things, and they would drop their coverage. So there came to be a lot of subterfuge in terms of how this was all reported and dealt with in terms of financial issues.

Hughes: So you'd be careful about identifying patients with AIDS?

Lewis: Yes.

Hughes: Can an insurance company get a T-cell count?

Lewis: They actually can get the count. Usually. It's a marker.

Hughes: So insurance companies learned to ask for the count?

Lewis: Yes, exactly. I don't know if they had learned that in the first years--certainly not in '81. Maybe beginning in '82. By '83 they were getting more and more savvy about it. Because I was doing my work with AIDS from a perspective of education and volunteerism, I was not directly involved in that, except peripherally hearing people complain about it.

Hughes: The KS [Kaposi's Sarcoma Research and Education] Foundation encouraged people to immediately get medical insurance.

Lewis: Yes.

Hughes: Did that mean that the insurance company, after issuing the insurance, could discover that the person had a low T-cell count, and drop insurance coverage?

Lewis: I don't think they knew what the T-cell count meant at that point in time. It could not be identified as a preexisting condition, because usually you have to have the insurance for a year or two or so.

Hughes: The technology itself was very new.

Lewis: Exactly. Nobody knew. I can remember talking to people about, not only insurance, but getting insurance for their credit cards, and all that kind of thing, so that they had their ducks in order when the time came and didn't leave a lot of financial burden.

Lesbian/Gay Health Care Workers Conference, Houston, June 1982

[Interview 2: July 6, 1995] ##

Hughes: Can you tell me how you happened to go to the Lesbian/Gay Health Workers Conference in Houston in 1982?

Lewis: Well, I was in nursing education and beginning to do education on AIDS with hospital staff, and also planning the conference that we had in San Francisco in June 1982. I think that conference was the first nursing conference on AIDS. The one in Houston was more general; it wasn't specific to nurses.

Hughes: Yes, it was for health care workers in general.

Lewis: Right.

Hughes: Including physicians?

Lewis: Oh, yes. There were never very many physicians there, but it's often held in conjunction with the BAPHR national meeting, or it was in those days. It's not any longer.

Jim Curran was at this conference, and we all went out to dinner together. We saw statistics of the incidence and the frequency of the disease, the statistical information that CDC had, which was limited. I remember him talking about how major an epidemic he thought this could be.

This was when they were fighting over terminology, what to call this disease, because it was still being called GRID [Gay-

Related Immune Deficiency], and it was very much connected with "gay." As I recall, that evening at dinner there was a lot of that sort of discussion. There were physicians and nurses and other health care providers, probably about eight or ten of us, that went out to dinner together.

Hughes: Curran had given a presentation at the meeting?

Lewis: Yes. The CDC had several people there, and they made a presentation. The mayor of Houston, who I think was a woman, or someone from the mayor's office, made a proclamation about gay and lesbian health care workers, in a positive sense.

The way the conference was set up was the AIDS program ran at the same time as another set of conference material. I don't remember the session on HIV being well-attended, although it was certainly the major point of discussion and interest among those of us from San Francisco who had gone. I had gone almost strictly for the AIDS stuff, although as a lesbian I was also interested in other things. But the reason I was able to get the time from work was because of AIDS. So that's where my focus was.

Helen Schietinger

Lewis: Another thing that was important at that conference for me was that I got to spend some time with Helen. She and I had met early on. Did she tell you the story of how she got into Conant's office?¹

Hughes: No.

Lewis: I was sitting at my desk one day in nursing education and the phone rang, and a woman I'd never met said she was looking for a job. I don't know why Helen called nursing education; she should have called recruitment. She was real interested in the psychosocial aspects of nursing and counseling.

Marc had already announced that he was going to start the KS Clinic, and I was thinking about applying for the job, but I wasn't clear that that was really what I wanted to do. I said, "There is a job that I know about that would combine some of your

¹ Schietinger was nurse-coordinator of the KS Clinic at UCSF; she never worked in Conant's private dermatology practice. See Schietinger's oral history in this series.

interests, because people are going to need a lot of support and counseling, and it's research, and it's medical. But there's one thing that you would have to be able to deal with."

She said, "What's that?" I said, "This is a clinic for gay men, so you'd have to be able to deal with issues around gay men." She said, "Oh, I think I could do that." [laughter] We hadn't come out to each other at this point. Then she talked to Marc, or did whatever she did to get the position.

We met for lunch after she was employed, and then we came out to each other. But that lunch or two was about all we had, so we really didn't know each other until Houston. We went on the plane together and roomed together, because our departments were trying to save money.

AIDS Activists

Lewis: That's when I began to get a sense of the differences among people coming in to AIDS work. We were all drawn by this sense of a compelling problem, but we came from different places. Helen and many people in the epidemic came from a background of activism and of being part of social change. And then there were people like me, who was much more middle-of-the-road, politically non-involved, who were drawn by the tragedy of what was happening, and the fact that it was happening to gay men. I felt a real close connection with all that.

Grace Lusby, I think, had been involved in the anti-war protests. Our lives were just in a totally different realm. In Clearwater, Florida, which was practically the retirement capital of the world, and where Shirley and I lived before moving West, you didn't hear about war protests. They were not part of the world in which we lived.

Hughes: Did it take some adjustment on your part to work with a group that had a different background than you were used to?

Lewis: We had this common focus, and we brought different perspectives. Sometimes they were more radical than I was comfortable with. When we'd be in meetings and there would be conflict, I always tried to smooth things over. I don't like conflict. But people who are activists often find that energizing and engaging.

Federation for AIDS-Related Organizations

Lewis: At the Denver Gay/Lesbian Health Workers conference [in 1983], there was a lot of conflict when FARO, Federation of AIDS-Related Organizations, was formed. One of the big deals was that there had to be a male representative and a female representative from each city. Particularly some of the women would be so [pounds fist on table] right in your face, that this was what had to be, to have parity and so on. There were certain cities where there weren't many women involved in AIDS work, and in a certain sense, it seemed artificial to me when they insisted that a female representative had to be included.

In my mind, it was, Why are we spending hours going over this and being politically correct when there's work to be done in terms of taking care of people. Let's get on with the work. So some of that sense of needing to be politically correct and having parity I found awkward and uncomfortable at times.

More on the Lesbian/Gay Health Care Workers Conferences

Lewis: Community activists and health care leaders in an informal sense attend the health workers conference. They work in STD or abortion clinics--in a variety of venues. Now, the people range all the way from folks with a doctorate who are physicians and very well educated, to folks who don't have a professional health-related degree. And some of them are just street folks. It's a very wide-ranging conference.

That conference was important to me, because of meeting Helen, because of Jim Curran, because of the discussion about what AIDS was going to be called, because people were not happy with GRID, because they didn't want it related to "gay."

Hughes: The idea was that it was stigmatizing?

Lewis: Yes, definitely.

Hughes: Yet, at that point the disease predominantly affected gay males. There was no getting around that.

Lewis: Oh, yes, at that point.

Hughes: Did you think of it as a gay disease?

Lewis: In '82, yes, I think I did think of it as a gay disease. We were beginning to learn a little bit more, but we didn't know about HIV at the time. We didn't know precisely the means of transmission. We had a lot of suspicions, and certainly everyone in the know felt it was definitely sexually transmitted, that it definitely was an immune deficiency of some kind.

Hughes: By '82?

Lewis: I'm pretty sure. It's so hard to actually remember in context and in terms of dates. I remember Jim at our dinner that night in Houston saying, "This epidemic is not going to stay only among gay men; this is a bigger thing." He really gave a sense of urgency: it can't stay connected with only the gay community. It needed to be viewed more broadly, because other people in other demographic groups needed to know about it. We didn't know exactly about how to take care of yourself, but it was clearly connected with sexuality, and it was a killer. As soon as you knew somebody had it, they were dying. It was really like, boom. So there was a real sense of urgency.

Hughes: Did you have that sense of urgency before you arrived in Houston?

Lewis: Oh, yes. I had a sense of urgency from real early on. I got that from Marc Conant, from going to conferences with him. I sat in almost every week on an hour session with Paul and Donald--

Hughes: The KS Study Group.

Lewis: Yes, the study group.

San Francisco Health Department Committees on AIDS

Lewis: The health department director, Mervyn Silverman, also started a couple of groups. He had one group that was all physicians, his team to advise him. Then there was another group that Florence Stroud, the Deputy Director of Community Health Programs at the Department of Public Health, chaired. It was community folks, probably twelve or fifteen of us.¹ It was an informal group. I don't remember ever getting a letter saying, "Would you serve on this committee?" It was the kind of thing where you heard about

¹ Lewis was a member of the group, which in her curriculum vitae she calls the San Francisco Public Health Department AIDS Coordinating Committee, from 1982-1986.

it and you started going to meetings, and if you appeared, you were part of the group.

Hughes: You didn't have anything to do with Merv Silverman's physicians group?

Lewis: No. Well, this was all under Merv. Flo worked for Merv. She was his deputy or first assistant. And on rare occasion, Merv might appear at the door and say, "Hi, guys." Flo's group looked at the community aspects of this disease, the more psychosocial and political pieces. I especially remember Hank Wilson, a community activist who managed the Ambassador Hotel, where many people with HIV lived. He could really make clear the problems being faced by people in their everyday lives as they were struggling to live with this disease. And there were people from San Francisco General [SFGH], and the social service agencies--anybody who was interested. Of course, as the epidemic grew in size, people had less time to go to meetings.

Hughes: What sorts of things would you discuss at this meeting?

Lewis: Oh, we'd get a report and update; we'd get the statistics, how many new cases were reported this month. They'd go around the room and everybody could bring up anything they wanted. So if somebody needed help with an educational program, they might present it. The group also looked at coordination of services between the various agencies. I don't know if I was there as a UC or AIDS Foundation¹ representative, because by that point, or shortly thereafter, I think I was on the foundation board. Although I was not on the first board.²

Marc was very concerned with generating monies to be used. He had a vision of research being done by the foundation. His vision was that this group would be able to fundraise, and there was a very heavy emphasis on that. He got several well-placed society people on the board.

Hughes: Lia Belli was one.

Lewis: Yes, on the early board.

¹ Lewis was a member from 1983 to 1985 of the board of directors of the Kaposi's Sarcoma Research and Education Foundation, the predecessor of the AIDS Foundation.

² See Conant's oral history in the AIDS physicians series for discussion of formation of the foundation and the first board of directors.

Hughes: With the idea of fundraising or political clout?

Lewis: I think both. I'm sure there was some person living with AIDS on the board. Cleve Jones, who was on the board, hadn't been diagnosed yet.

People Living with AIDS

Lewis: One of the things that I really did support was having people who were living with HIV be part of the things that were happening. Like at Flo's group, they would always try and have someone with HIV there. Bobbi Campbell served that role in a number of venues after he was diagnosed. There were other people--Dan Turner and Bobby Reynolds--who served that role.

Hughes: Why did you think that was important?

Lewis: I had always felt that way. I had done conferences in the past, before HIV, on breast cancer or colostomies, in which the most effective part was having someone come and talk about what it was like living with that disease. I have always found that a very powerful teaching tool. No matter how well informed you try to be as an educator, there is something that impacts the audience in a different way when the presentation is by someone who is in that life experience.

Hughes: Yes, I can see that.

Lewis: At the June [1982] conference on Kaposi's sarcoma-Pneumocystis pneumonia there was a patient panel of I think four folks. I had always been really focused on that [patient participation] as an educator. [looking at conference program¹] Jim Geary [director of the Shanti Project] moderated it. It was a very powerful experience, because most of the people at the conference, even gay men, certainly the women health care providers, had never seen anybody with HIV. People get all kinds of images that are not real about what it's like and who these people are.

The other place that this connected for me was in my experiences talking to groups about being a lesbian. It humanizes the issue for people and gives it a face. I think that's a really important piece.

¹ Kaposi's Sarcoma and Pneumocystis Pneumonia: New Phenomena among Gay Men. UCSF, June 26, 1982. (KSN 3-12/1982)

Gay men for the most part were used to being empowered; they were used to making their own decisions, being their own bosses, used to not being told what to do. Many of these men had played by the rules: they had finished high school, gone to college, gotten their degrees, established their careers. And now life wasn't treating them the way they expected to be treated.

That turned a number of gay men into very powerful activists. They took their strength and their life experience, and they used it in very powerful ways. I think it has really impacted things in health care, at least in this area. I can't speak for the nation, but I think it's pretty well established that visiting rules in critical care are being stretched, are being changed, and much of it as a result of this activism.

Things like having people stay in a hospital room overnight. You used to let a mother stay with a child, but you didn't let an adult stay with an adult, for the most part. And now that's being changed for everybody in many, many places. People would know their lab work up and down. They went to the UC library and read up everything that was published on HIV. And patients communicated with one another across the United States.

That whole sense of secrecy, of knowing something that other people don't know, also applied to patients. They had a very tight-knit community. There was a point in time, and it was in Houston [1982], and even in Denver [1983], when you had a sense that you knew everybody who was working in this field. People had a very strong aversion to being called patients. They wanted to be persons with AIDS.

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Lewis: There was a two- or three-page manifesto from the people living with HIV about their bill of rights, and that's basically what it was. That was written at Denver by the men themselves. They had sessions by themselves without any health care providers or other people there, where they wrote that. It's a very powerful document. The AIDS Foundation would surely have it.

They said, "I am a patient only when I am in a hospital bed. I am not a patient when I am in your office, or when I am out in the community. Then, I am a person living with this disease." They were very adamant about that. I think that was a very strong and powerful and important thing that they did for health care, that sense of moving away from the role of dependency and reliance on health care professionals to take care of you throughout your life or when you've got a terminal diagnosis. As opposed to, "I am in charge of my life. I will become informed, and I will make

these decisions." I've heard discussions from patients with other catastrophic illnesses who are demanding their rights and what is due them.

Hughes: And you think that attitude stems from the AIDS activists?

Lewis: I really do.

Hughes: So it was really happening on two fronts: patients girded themselves psychologically to be potent, not to be the dependent patient. They also created ways to exchange information, to become informed about the disease, to a degree that had not been true before.

Lewis: Yes.

Hughes: Patients became a source of information about the disease.

Lewis: That's right.

Hughes: And in some cases, even knew more than physicians.

Lewis: Yes. They were very well informed. As a health care provider who's not into science so much, it was really intimidating to me a lot of times, because they would know so much more than I knew. But that was what their lives revolved around. That was the focus of their lives. Many of them had a lot of personal computer savvy, so they would be able to use their modems to access information. I think the National Institutes of Health had certain ways that you could access information. I don't know for sure, because I wasn't using them myself.

Hughes: Well, the KS Foundation early on compiled a bibliography on AIDS. It's an indication that there was a need for information. Was it used by people living with AIDS as well as physicians?

Lewis: Yes, absolutely. It was used by everybody. The volume of material was small enough at the beginning that one could reasonably, with diligence, expect to read everything--for a little while. Obviously, it didn't work very long, because the information just burgeoned. But there was a time when you could reasonably have read everything.

Hughes: Did people with AIDS come to you with pre-existing ideas of what they thought the course of the disease was and what its cause might be. Or was it more, "I have a lesion," or "I can't breathe properly," and that was the focus of their concern?

Lewis: The patients that I saw for the most part were relatively healthy. I saw some people in the hospital on a one-to-one basis. At that point, they were always quite sick. The other folks that I saw were well enough to be out at meetings.

I was not in a physician's office or in a clinic situation where I would see somebody over time to watch the status of their physical situation. I was more involved with folks who were in the community--I tended to be involved with activists. If somebody wasn't going to meetings, I probably didn't meet them. I met people living with HIV as a consequence of the AIDS Foundation or setting up conferences and trying to find people to sit on panels, that kind of thing. I did have relationships with a few people with HIV, but for the most part, the people that I knew were the activists.

Hughes: You would be unlikely to encounter people in denial, for example.

Lewis: Oh, absolutely, yes. I had no way to interact with those folks or to know who they were. Nor did I, for the most part, know patients in terms of their day-to-day care in the hospital, or in the doctor's office. I was not a nurse at the bedside; I was not a nurse working in a physician's office, or in research like Helen was at one point. [interruption]

Grace Lusby was an infection control nurse at San Francisco General, so she met people at their bedsides. Helen was seeing patients at Marc's office, and following them.¹ I was one of the few people that I know of who was a full-time health care provider but involved in the epidemic in a totally different role.

UCSF School of Nursing Support for AIDS Education

Hughes: How was it to try to integrate your AIDS work into what the university expected you to do as a nurse educator?

Lewis: Actually, they were quite generous, I would say. Helen Ripple was the director of nursing, and she was very supportive in terms of my doing conferences. For example, she funded me to go to Houston. I would write a request to go, with an estimated budget, and I almost always got them approved.

¹ Helen Schietinger saw patients in the KS Clinic at UCSF; she never worked in Conant's private dermatological practice.

Hughes: Was that because she recognized the importance of the epidemic?

Lewis: I think she did.

Hughes: She thought the university should be involved in the epidemic?

Lewis: Right. That was my impression. [tape interruption] She was very supportive in terms of funding to go to conferences, in terms of time to attend meetings, to be on Merv's committee or whatever. If I left work early or went off to do something, it was never an issue. She wasn't my direct boss; she was the director of nursing, and then under her was the head of my department. But I always had a sense that there was support that flowed down.

Hughes: That must have been true of the first conference.

Lewis: Oh, yes.

Hughes: It got off the ground because the School of Nursing was supportive?

Lewis: This was not to do with the School of Nursing. I wasn't in the school. I was in inpatient service.

Hughes: Oh, I see.

Lewis: I was in nursing education and research, which meant that we oriented all the new employees; we put on conferences. At any one time, as an educator, you would be juggling several balls. As a group, we would sit down quarterly or every six months and plan our educational programs for the upcoming months. We were given latitude to say, "Oh, I want to do a conference on this," or "I think we need to do this." If you could make a cogent argument, they'd say, "Go ahead." I had said, "I think we need to do a conference on AIDS," and everybody said, "Yeah, go ahead."

More on the June 1982 Workshop

Lewis: I remember this particular conference was intensive. In most conferences, a nurse educator pulled together a group of speakers, and this person did this topic, and this person did that topic. That meant that as the coordinator, all you did was introduce people. In the preparatory work, you got out the programs and you advertised, but you didn't have to do too much more.

In the [June 1982] conference, we had two case studies. One was a patient with Kaposi's, and one was a patient with Pneumocystis. We had to create the actual case study to hand out to people. So I coordinated development of those case studies. The one on the Pneumocystis patient involved a respiratory therapist, a nutritionist, a social worker, and a nurse, so it was a lot of work to get all the information together.

Hughes: Do you remember who came? What disciplines were represented?

Lewis: Nursing, it would be primarily. It was advertised, as I recall, also to respiratory therapists. They had a CE [continuing education] requirement, and we got CE hours for respiratory therapists. It was advertised to social workers. My guess, and I don't have any statistics that would support this absolutely, but that 80 percent, perhaps as high as 90 percent of the people who attended were nurses. And I suspect that we had 120 people attend. We used a double room in the School of Nursing.

Another thing that was different about this workshop was that we did it on a Saturday. Most conferences that my department presented were during the week. This one we did on a Saturday because we wanted to connect it with the Gay Freedom Day parade, which was that Sunday, June twenty-seventh. We felt that a lot of people might have trouble getting off work to attend a conference on a subject that that was not well known and not perceived by the health care population as a major problem, and the workshop title mentioned "gay."

We provided a catered lunch, and that was unusual. It cost fifteen dollars for a UC employee to attend, with lunch and coffee break and everything else! [laughs]

Hughes: Do you remember the audience's reactions?

Lewis: Oh, it was very powerful. People really were blown away. It was a very well done conference. Helen did a little blurb on KS and PCP for fifteen minutes, and then we had Judy Harr, who now is an educator over at USF [University of San Francisco], talk on immunology. She is one of the best educators I've ever seen. She just grabs an audience. She has a real understanding of the immune system, and she loves hard science.

Then we did two case studies, which are very engaging because you're hearing about an individual. We had a panel discussion for each case and each of the speakers had ten or fifteen minutes to talk about their view of the case. Then there was discussion and questions, so that the audience was really engaged. By ten o'clock, all the lectures were over. As soon as they came back

from coffee break, then they started into the case studies, which gave an opportunity to be interactive.

Then we had a lunch, and then we had another case study. Then they heard the patient panel, and then I did a close on taking care of ourselves, which had to do with sexuality and political activism and being there for people.

Hughes: But not infection control?

Lewis: I don't know if we had infection control per se. Linda Rosendorf an infection control nurse was on the panel on the KS patient, which was based on Simón Guzman.

Hughes: Did you make new connections with people at that conference?

Lewis: Yes, both at the conference and planning for it. For the most part, the people who attended went back to their jobs and did whatever they did. In addition to meeting many of them, I made new connections with folks such as Margaret Walter, R.N., a staff nurse who helped write the case studies and did a presentation as a panel member. Basically, what I did was talk to the head nurse and the people who were at the bedside caring for patients to find out who might be good to do this kind of presentation.

Marty Hill, the respiratory therapist who presented as part of the PCP case study, was actually over at San Francisco General. We got him to talk about what his experiences were, even though it was with a different patient.

Hughes: Why didn't you invite somebody from UCSF?

Lewis: I don't remember. We had a planning committee. That's where this idea of case studies came about. You say, "Well, if we want to have respiratory therapy involved in this, who would be good?" And his name came up.

AIDS Activities at San Francisco General

Hughes: The AIDS Clinic at San Francisco General didn't open until January, 1983. But patients with KS and PCP were being seen there before then. Were you aware of what was going on at San Francisco General?

Lewis: Yes. I was hearing about it at Flo Stroud's meetings. A big part of the discussions at those meetings was, should there be a

separate unit for people with HIV, or should they be integrated into existing units? And is this stigmatizing, or is this supportive? And there were many, many hours of discussion along that line.

Hughes: What was your opinion?

Lewis: I was generally of the opinion that people with HIV should be kept separate. I had seen too many instances of--because if you integrated into the general population of a hospital, in those days, I think it would have been a lightning rod for people who were homophobic, who were right-wing Christian you've-got-to-change-your-life kind of people, to be totally nonsupportive. I could recognize the fact that the disease was stigmatizing, but I was certain, as did turn out to be the case, that many of the staff who would choose to work in the unit would be lesbian or gay themselves, because of their desire to support the people who were living with HIV.

Hughes: Well, that had been your experience thus far.

Lewis: Yes.

Gay Community Involvement

Hughes: It seems from what you're saying that in San Francisco it's not only a gay disease, but, with notable exceptions, the people who are primarily involved with the epidemic are gay as well. Would you say that's true?

Lewis: I would say that was true. There were certainly many, many exceptions, Grace Lusby being a prime example and certainly the folks from the health department, Merv Silverman and other people who were absolutely outstanding. But those of us who became involved at the level of community activism--I mean, I'm sure there would not have been a conference [at UCSF] had I not been there.

Hughes: Were existing lines of communication between the gay communities on both coasts being used or were new links forged?

Lewis: I think they were new. [tape interruption] There were some existing links, because the gay and lesbian health care workers' conference occurred before HIV, so there was a group of people nationally who were interested in gay and lesbian health care and health worker issues.

Hughes: And there was BAPHR.

Lewis: And there was BAPHR, Bay Area Physicians for Human Rights. They were a national organization. So there were those two pre-existing groups. There was quite a bit of rivalry between the San Francisco AIDS Foundation and GMHC [Gay Men's Health Crisis] so there was not an effort to link those two really closely.

I remember Marc real early on having a roughly drawn map of the United States, showing San Francisco here and New York here, and drawing a line and saying, "The San Francisco AIDS Foundation"--it was the KS Research and Education Foundation at that point--"will be established and everything will come to San Francisco." He saw the foundation as being the key national AIDS organization.

Well, New York didn't see it that way at all. [laughter] They saw it very differently. So there was a tension that existed for some period of time between the AIDS Foundation, as it originally was envisioned, and GMHC.

In terms of the links that were formed, they may have derived in some portion from the gay and lesbian health care workers' group, much more from that than from BAPHR, I think. BAPHR docs may have had connectedness from a scientific standpoint, but not from a political and organizing standpoint.

FARO was a federation of local AIDS organizations. It was an attempt to try to connect all these groups together in a federation, where each would maintain its autonomy and its organization relative to its local community but be able to share resources--everybody was reinventing the wheel. Everybody had to have educational material to put out to people, and instead of twelve different groups writing their own material, there ought to have been a way to get yearly updates that were handed out to everybody.

Hughes: Did that indeed happen?

Lewis: Well, it was not very successful, primarily because of funding issues. And then a lot of people questioned whether there was really a need for the group and was it effective, and how could small-town groups be involved? I was one of the female San Francisco representatives--the first one, as I remember--and Bobbi Campbell was the male representative.

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Lewis: We met three or four times a year. One of the major questions was: who was going to pay for those airline tickets? Maybe the AIDS Foundation could afford to cough up a couple of airline tickets several times a year. But if it was a small organization struggling away, which hardly could raise enough money to maintain a facility, it just didn't have the resources.

So that meant that a few organizations, like GMHC and the San Francisco AIDS Foundation, dominated because we were the ones who had the people at the meetings. So there was a lot of jealousy. And then sometimes a group could send one person but not two, so then did they send the woman or the man? And if one came without the other, particularly if the man came without the woman, then that was not okay. The group could be quite contentious, because almost everybody had very strong feelings and were very vocal about them. The meetings would drag on for endless hours.

FARO served a purpose for a limited time, although it did not meet its grand purpose, and finally just died away.

Hughes: Did GMHC also have national aspirations?

Lewis: I don't know. I didn't hear about that. GMHC has in many ways moved in a different direction. They actually do a lot of direct care provision, from what I hear. I think they incorporate Shanti psychosocial support kinds of things.

Hughes: Under many roofs.

Lewis: Right. I think one of the reasons the federation was not real successful was because the organizations were so disparate in their needs and their interests and their goals.

Hughes: FARO no longer exists?

Lewis: It died its natural death after about two years. But a lot of the same people are still involved in HIV, I think, and the local organizations still exist, for the most part. I'm sure they've come together to do lobbying, which was part of what FARO was supposed to have been about. It was supposed to lobby and to develop a legislative agenda for HIV, because no one organization, even one as strong as the GMHC or the AIDS Foundation, had the resources, financial and otherwise, to do that. At the time, we just didn't have the resources to support FARO in the way it needed to be supported. I'm sure there is an organization that does that now.

Hughes: Well, AmFAR [American Foundation for AIDS Research] does a lot of lobbying.

Lewis: That's true.

Hughes: I came across a memo from Conant to you which was dated July, 1982.¹ He asked you about giving an in-service at San Francisco General for nurses handling patients with KS and PCP.

Lewis: I don't remember giving that. But six months or something after the June 1982 workshop, we did another one at San Francisco General, to give both venues the information.

Hughes: Obviously acknowledging that AIDS patients were being seen at both institutions.

Lewis: Right.

Tensions between UCSF and San Francisco General

Lewis: I assume that you're aware of the tension between UC and General?

Hughes: Well, please talk about your perceptions of that.

Lewis: I don't know a whole lot about the inner workings. I know that as a nurse at UC from 1975 on, San Francisco General was just sort of "over there." It was never looked upon very favorably. It was a place where residents and interns had to rotate through, but they always were anxious to get back to UC, to the "real" place. So you never had a sense of General being part of the UC family.

Hughes: It was the county hospital.

Lewis: It was the county hospital. In fact, I don't know if I was even aware of how many UC people, paid by UC, have their offices there and work there full-time. I don't think I had any understanding of that at all. I was a head nurse; I was in the hierarchy, but it just wasn't anything that you had an awareness of at UC.

I just couldn't understand why all of the AIDS activities were going over to General. It was like, "Wait, what is going on? Why is this happening? Why not take a medical unit here at UC and make it the AIDS unit?" But it was very clear from the get-go that AIDS was going to be at General.

¹ Marcus Conant to Angie Lewis, July 29, 1982. (KSN 3-12/1982)

I think the health department supported that. I'm not sure what came first in terms of the health department wanting the AIDS unit at General, or UC not wanting it.¹ I wasn't privy to any of that. But as part of Flo Stroud's committee, I was privy to discussions that went on internal to that committee, and UC was just not discussed. It was like, it's going to be at General.

Hughes: Why was that such a certainty?

Lewis: I'm not sure. That's the kind of discussion I was not privy to. This tension between UC and General is something that very few people know about. I heard a very good presentation Marc Conant gave at Langley Porter Psychiatric Institute seven or eight years ago about what happened at UC, and his perception of the Department of Medicine and the dean. The decision was made at that level, way beyond anything I was aware of.

Marc gave a very articulate description of the situation and the difficulty he faced in trying to get the university to acknowledge that AIDS was a problem and that we needed to put resources in it.

I mean, when UC finally did open an AIDS clinic, it was called the Adult Immunodeficiency Clinic. It was like, Give me a break! Adult immunodeficiency--because we can't call it AIDS. We can't say the word, and have it up here on the hill.

Hughes: Did you experience homophobia on a personal level?

Lewis: No, I did not personally have that experience. The Nursing Department was very supportive. Helen Ripple was supportive, my boss was supportive, and I was given a lot of freedom and flexibility and encouragement to do what I wanted to do. They saw a real need for nurses to be educated, because we were seeing HIV patients in the inpatient units. Guzman was at UC.

Hughes: Now, was that because he was an early patient?

Lewis: Yes. That was before there was a 5A [inpatient AIDS ward at San Francisco General] or anything like that.

Hughes: A patient who presented at UC would be shuffled over to the AIDS Clinic at San Francisco General?

¹ See the oral history with Marcus Conant in the AIDS physicians series for his view on the decision regarding location of AIDS units. Lewis uses "UC" to mean exclusively UCSF, even though SFGH is jointly administered by UC and the San Francisco health department.

Lewis: If someone were sick enough, he would certainly be admitted to UC. I mean, if he was critical care. Someone who didn't have any resources would have been encouraged to go over to General. It was fairly well publicized in the gay community fairly early on that there was an AIDS Clinic over at General and that an inpatient unit was opening. That was all in the gay press. That meant that ambulance drivers would know that that's where somebody with HIV probably ought to go. So the information got disseminated, and that then decreased the number of people who might have come to UC.

Now, of course, UC does have this Adult Immunodeficiency Clinic and now has a quite active AIDS service.

Hughes: What's the breakdown? People come to UC if they can pay for it?

Lewis: I don't quite know what the breakdown is. Part of it is that, but they do take Medi-Cal. A university hospital has got to do that. I think part of it is where people feel more comfortable.

Changing Patient Demography

Lewis: Ward 86, which is the AIDS clinic at General, has really changed pretty dramatically over the years. Now maybe 20 to 30 percent of the patients, maybe even 40 percent, are minority.

Hughes: And not necessarily gay?

Lewis: And not necessarily gay. Some are gay. There are a lot of IV [intravenous] drug users. The demography has changed quite dramatically over the past four or five years.

They still get some of the middle-of-the-road gay white men, which is what their population was initially 95 percent of the time. But it's really changed a lot, and it's made it very hard for the providers who went into this with their initial impetus being a sense of connectedness with patients who looked and sounded and felt a lot like them, to a population now that is very different. Some people, like Gary Carr and J. B. Molaghan,¹ who have been there over the years make that transition very well. But it's been difficult, I know.

¹ Carr and Molaghan are nurse practitioners at the AIDS Clinic at SFGH. See Carr's oral history in this volume.

Hughes: And probably some people did drop out.

Lewis: Oh, yes. But it's very hard to separate out how much is due to a natural burnout, and how much to the changing demographics and face of the epidemic.

Fear

Hughes: Well, talk a little about fear. In your educational endeavors, I imagine that there was a fine line between imparting the significance of the epidemic, and not overly frightening people.

Lewis: Well, it was something that needed to be acknowledged pretty early on in any presentation you were doing, particularly in the very early days when we really didn't know the mode of disease transmission; we didn't know how to prevent it; we didn't know anything.

Hughes: And the disease was scarier, because of ignorance?

Lewis: Yes, not knowing. Shades of grey, which I used to talk about, are very frightening.

Hughes: More so than, "All right, we have a virus"?

Lewis: Much more so, because once you know what it is, then you feel you can control it and take some steps. When you don't know, then it's very, very frightening. Content was such a small part of an educational presentation, because much more had to do with dealing with fear and unknowing, dealing with homophobia, and trying to humanize that piece for people.

Disease prevention dealt with sexuality, or at least at that point in time. It didn't move into drug use, which is a little different. But at that point in time, we were dealing with sexuality. All you have to do is hear [Senator] Jesse Helms in the past week talk about this "disgusting, horrible behavior [homosexuality]." Well, there were some people, and still are, in the educational venue who felt, "Well, they [gay men] just need to stop. It's their own fault, and why don't they just stop?"

One of the things we looked at in AIDS prevention was how to be sexual in different ways. If you were talking to an audience of gay men, your messages were quite different than if you were talking to an audience of health care providers that was basically

straight women from the San Francisco peninsula. You had to deal with different issues with each of those audiences.

You didn't get up and talk explicitly about sexual behavior. We had a series of exercises that evolved over time, like helping people realize how difficult it is to change behavior. We all know what helps keep you healthy, so how many of you this morning flossed your teeth? How many of you only had X grams of fat in the past twenty-four hours? How many of you took a walk or did your exercise? How many of you smoke? We looked at those changes that any of us find extraordinarily difficult to make.

And then, taking sexuality and saying, "Now, someone says to you, 'But you can't ever have intercourse again.'" We tried to help people think about those issues, rather than just saying, "But all you have to do is stop." We took it away from the realm of being an absolute, "It's so simple, just stop," to having people think through, what would that mean in your life? How in the hell does anybody stop?

Hughes: Could you get through at that level?

Lewis: Sometimes. Certainly not to everybody. I don't even know if you got through to most.

When I was assistant director of nursing [1986-1988] at Langley Porter [Psychiatric Institute], I did do educational programs for the housekeepers. They were all black men, poorly educated, and they were convinced that AIDS was some kind of white man's revenge. There you had to deal with issues of, "Well, everybody says this came from Africa." You never knew what you were going to deal with in a workshop [laughing]. But it generally boiled down to fear, homophobia, and sex. You had to be able to deal with those issues in a public situation.

Hughes: An individual's fear of getting infected?

Lewis: Yes. It was fear for themselves and their families. It was a very real thing. I had felt it.

Hughes: Yes, you had.

Lewis: And one of the things that one often did in a presentation was talk about fear, and the fact that we've all felt fearful, and that part of living is being fearful at times, and that we need to use fear to keep ourselves safe. You don't go messing around with needles and sharps and fluids. There are times when it's reasonable to wear gloves, to wear gowns, to take full precautions.

But that doesn't apply to going in and holding someone's hand. It doesn't apply to sitting on a bed. What a lot of people did was transfer their fear of catching the disease to the person with the disease, and then that's a way of distancing that person. Part of every conference very purposefully would be, when people finished their presentation or panel discussion, for myself or whoever had made the announcements to go and hug people with HIV, as part of saying, "Thank you for being here, et cetera." Or whenever a person with AIDS came into the room, I made a point of holding them and being there physically with them. I think that role modeling behavior is an important thing to do.

When I went to visit Simón, I would sit on his bed, and I would take my gloves off. We were wearing gloves at that point;¹ I don't know if we were wearing masks. At that time, nobody knew anything about the disease. It could have been airborne; we didn't know. But it was important to me to demonstrate to the staff, to touch, even though I didn't quite know what I was doing --maybe it really was dangerous.

Simón was really quite sick when I was seeing him. Although we didn't speak the same language--he only spoke Spanish--I would sit on the bed or pull a chair very close and hold his hand, and just sit in silence. I think I demonstrated to staff that personal connectedness is really important, even for somebody where you have to go in in full infection-control regalia.

It could have been dangerous. It could have been transmitted by touching. But I was always real careful to wash my hands as soon as I left the room, because we didn't know. I always have felt that skin-to-skin contact is so important. People living with HIV were very eloquent that not being able to touch was just so painful, and that loss of connectedness with people.

Hughes: I know there was a lot of controversy in the gay community about safer sex education.

Lewis: Oh, tons.

Hughes: Was this a subject discussed by Flo Stroud's committee?

Lewis: I don't think we talked about it so much there. Much of the discussion around this was actually in the gay press. If you go back to the BAR [Bay Area Reporter] and the Sentinel [San Francisco] of those years, the letters to the editor, the

¹ Guzman died on March 25, 1982. (Shilts, And the Band Played On, p.137.)

bathhouse issue was a huge issue. That did come up at Flo's committee.

The line I remember from the June 1982 workshop was when in that last presentation I said, "And don't rim strangers. It's just not safe." I remember three women coming up afterwards and saying, "And what's this rimming?" [laughter] "Well, let me tell you." When I did educational conferences, generally it was more at the level of how might one be sexual without exchanging fluids, which in some ways is unrealistic, but in other ways, that is safe.

The bathhouse question was a community debate, and not just in the BAR and the Sentinel but also in the Chronicle and Examiner. I mean, it was like everywhere. Generally, I didn't get into it during educational presentations, but I did go to some meetings. I went to one meeting at UC that was about the baths, with community activists.

Multidisciplinarity in Medicine

Hughes: One of the unique things about AIDS activities as they started at UC, and then later when they became more formalized at San Francisco General, was a multidisciplinary approach. Had you been associated with a medical effort that incorporated different disciplines? I'm thinking about the San Francisco model of comprehensive AIDS care that eventually evolved.

Lewis: No, nothing that elaborate. My focus prior to HIV was OB [obstetrics]. Certainly in women's health care and in care of families many disciplines are involved, both in the hospital and in the community. There was some community involvement in terms of public health nurses and some community support, like La Leche League. So there are some models that incorporate a variety of disciplines.

I think that my experience in OB was an asset in terms of HIV, because a lot of people involved in AIDS had not had experience that involved a number of disciplines or the community in the way that I had had. I had been very involved in trying to establish a free-standing birth center in San Francisco and services that involved a lot of community people. I had done the same sort of thing in Seattle.

So yes, I think I had seen a model that was less comprehensive than what AIDS has evolved to, but that gave me a

leg up on a lot of people, in terms of envisioning what it might be or a direction in which we could head.

I also believed that none of us knows everything and that we all bring our piece, and that we have to really encourage other people to contribute their ideas and/or expertise. I think one of the roles that I played was encouraging everybody to do their best and give what they could give. We don't each have to know everything, and we all learn from each other all the time.

When I did the book,¹ it was up to me how I wanted to put it together. We really got a very wonderful group of people together to address a variety of questions, and it was their expertise that determined where the book was going and what needed to be in it.

Hughes: Did you choose the contributors?

Lewis: Yes. That's one of the roles of the editor. I put out a call to people that I knew saying that I was going to be doing this. I guess I put together an outline first and then sent it out in a series of revisions, asking people to contribute and give me ideas on who would be good authors. It evolved as a group effort. I'm good at getting that kind of thing organized and orchestrated.

Hughes: It's a very powerful book.

Lewis: Yes. Having a chapter by a person living with HIV was very significant and unusual. That was something that I had not seen modeled. If you look at medical books written at that point in time, you never saw a chapter by a person living with whatever the disease was.

Hughes: Has AIDS made an impact in that area, too?

Lewis: I don't know.

Hughes: Well, the value of the multidisciplinary approach, particularly in a multifaceted disease, seems pretty evident. But on the other hand, were there day-to-day logistical problems in working with an array of different people, coming at the disease from quite different perspectives?

Lewis: Yes, and logistically tremendous difficulty. I mean, to have a planning committee for a conference is really difficult where you got people from San Francisco General, people from UC, and nurses

¹ Nursing Care of the Person with AIDS/ARC. Angie Lewis, ed. Aspen Publications, 1988.

and social workers and nutritionists who each had their own schedules and lives and responsibilities, and managers who might or might not be supportive. The same thing applies in the community. Putting the hotline together at the AIDS Foundation, and getting that coordinated on a totally volunteer basis, was very difficult.

It was logistically difficult from my perspective, because during those early years of the epidemic, I was living in Woodacre in Marin County. Shirley often talks about how many hundreds of movies she sat through while I was at meetings. Our jobs at UC ended around four or four-thirty. Most meetings would start around six-thirty or seven. So we'd go out to dinner, and then she'd go off to a movie while I went to the meeting, because it was silly to drive two cars into San Francisco.

Hughes: Did you think that health professionals recognized the importance of having a multidisciplinary and comprehensive approach to AIDS, or did they see the epidemic pretty much through the lens of their specialty?

Lewis: Well, physicians tend to be very egocentric, and I don't think it's any different in AIDS than in anything else. [laughter] I think they appreciate and see value in other disciplines, but they see themselves as the leader of the team.

The San Francisco Model of Comprehensive AIDS Care

Lewis: Now, the multidisciplinary approach was not as obvious at UC as it was at General. It was really at General that it began to evolve into something unique. In caring for patients up on OB at UC, we had the social workers; we had nutritionists; we had chaplains; we had ethicists; we had physicians; we had nurses. UC, and university hospitals in general, tend to operate in a multidisciplinary mode. So I don't think that was a great deal different when I worked with AIDS patients at UC than what I had seen in the past.

Where it became quite different was as 5A was organized, and I think as you talk with Cliff Morrison¹ you will gain an appreciation for the uniqueness of how that was organized.

¹ Morrison is largely responsible for planning and organizing Ward 5B, the inpatient AIDS unit at SFGH, which opened in 1983. In January 1986, the unit moved to Ward 5A. See Morrison's oral history in this series.

Everyone, including the housekeeper who cleaned the unit, was part of their group and went to their meetings. Everyone was seen as a valued member of the team. Now, you would not have found that at UC. You would not have found that at San Francisco General outside of 5B.

They set up things to help the staff members. For example, they had support groups. They had special arrangements for staffing, where people could take breaks when they felt overwhelmed. Many parts of the 5A model that Cliff developed are still in action; some aren't. They were more expensive. They were labor-intensive. They require extra staffing, and I think there was some jealousy from nurses in other units and in other venues.

I think that HIV and AIDS did actually impact the nursing profession more broadly. I heard on the news in the past few days that [Senator] Jesse Helms and [Representative Newt] Gingrich are talking about a disproportionate share of research funding going to AIDS and that the patients are getting too many services. There has been that sense among some people all along, as the multidisciplinary model evolved and became more and more complex.

There are, in fact, services and resources for people with HIV that are not there for other people with terminal and life-threatening illnesses in their families. And there has been a sense among many people that that isn't fair, that the playing field ought to be leveled in some way. I think that is going to be a debate that we're going to hear in the coming months, because clearly, as they're trying to decrease the [national] deficit, they're looking at how we spend our health care dollars. Giving people the range of services and the multidisciplinary approach that has been the model for HIV, which--. You could look at the other side and say, "Why don't we use this model for everybody?" But it is expensive.

At one point, many of those dollars were from private donations and from the resources of the gay community, but it's gone beyond that and the community has broadened now. When it was almost all gay men, and white gay men at that, then other white gay men felt a need and desire to contribute and to be there. That has changed somewhat, and the generation that had that sense has either died or they're older and they're dying of other causes or having their own life problems. And people just wear out. Whether it's AIDS or cancer or whatever, people do wear out in terms of giving and being there for people.

Hughes: Am I understanding you to say that what happened at San Francisco General was different because people working in AIDS were all

physically located in one spot, on a team, in a coordinated sort of way? Where the image I get of what happened at UC was sure, there were different disciplines involved, but there was no central place; there was no central team. Marc Conant went back to his dermatology practice; Volberding went back to his oncology patients at San Francisco General. It wasn't a cohesive, coordinated effort.

Lewis: Yes, that's a very good assessment. UC didn't have the resources, or was unwilling to devote resources, to establishing and maintaining an AIDS clinic. When they did establish one, they wouldn't use the AIDS word, but had to call it the Adult Immunodeficiency Clinic. Marc Conant would have been very happy to develop an AIDS clinic at UC. He would have been very good at it. It wasn't just a KS question; it would have required other physicians like Volberding with his oncology. But UC had no interest in providing a coordinated approach. Then there was San Francisco as a city that gradually developed this integrated approach, with the Visiting Nurses [Association] and hospice and the AIDS Foundation and San Francisco General.

Communication between the AIDS Clinic and Inpatient Ward at San Francisco General

Lewis: Interestingly enough, there wasn't a lot of communication between [Ward] 5A, which is the inpatient unit, and [Ward] 86, the outpatient clinic. I worked on 86 with Donald Abrams' Community Consortium¹ [1991-1994], and so I was up there a great deal. There was more connectedness between the two units, but at the same time, a lot of the people--. You'd say, well, you heard that so-and-so was in the hospital. Well, nobody really seemed to know too much about it.

They are both extraordinary units and I have great respect for them, but there isn't that connectedness that one might have thought that there would be. I don't know the history of that.

¹ For information on the San Francisco County Community Consortium, see Abrams's oral history in the AIDS physicians series.

More on Bobbi Campbell

Hughes: Would you like to talk more about Bobbi Campbell?

Lewis: Bobbi Campbell was quite an incredible man. Absolutely flaming faggot. [laughter] And proud of it. Sister Florence Nightmare.¹ Sister Flo, we called her a lot. Bobbi was very politically astute, very much a mover and shaker.

Hughes: As of the AIDS epidemic?

Lewis: No, I think before. I mentioned that I used to do classes in the School of Nursing on human sexuality, and I know Bobbi had done programs there also. So I know he had been out, and I'm pretty sure at his university, he had been active. So I think he had a history of activism and political awareness.

He certainly was very much a mover and shaker once he was diagnosed, and he made a conscious decision that he would be the AIDS poster boy. I met him very early on at one of the KS Study Group meetings that Marc Conant had, when he came in as a patient and his case was presented. He had had a very bad case of herpes simplex, and he had a lot of scarring on his face. He had been hospitalized, and that was when they had first realized that he was ill. It was subsequent to that that he was diagnosed [October 1981].

Hughes: You mean, from the herpes they deduced AIDS? Or whatever it was called then.

Lewis: It's hard to remember what the right terminology was with the right year. Yes, that's how he was diagnosed.

Bobbi was very articulate. He and I did a presentation in New Orleans at the American Nurses Association [ANA]. Bobbi and I were asked to present at the last minute. The two of us submitted a proposal, and didn't hear from them for an extended period. We assumed that nothing was going to happen, and then got an invitation days before we were supposed to go. So it obviously was something that the ANA wasn't clear that they wanted to do.

We made a fairly major presentation, which was well attended. I remember we were in the large auditorium, so it may have been a plenary session. There were hundreds of people. I think I gave

¹ Campbell was a member of the Sisters of Perpetual Indulgence, a gay street theater group, whose members dressed in nuns' habits.

the introductory didactic piece, and then Bobbi gave the I-am-the-person-living-with-HIV piece. I think we might have had forty-five minutes or an hour. We got a good response in the evaluations. We got a couple that were very upset--

Hughes: Because?

Lewis: Oh, that the ANA invited queers--those anonymous statements that you get occasionally. You just have to put them aside and not let them bother you.

Bobbi was probably the prime author of the People with HIV bill of rights. He always liked to get out there and be very articulate and use very feisty language. He was a mover and shaker in terms of orchestrating that kind of thing. He was very ready to always be out there. You know, he was on the cover of Newsweek.¹

Hughes: Yes, I realize that.

Lewis: He liked that attention. He was interviewed a number of times by the national press.

Diseases Diagnostic of AIDS

Lewis: I met several men who had been diagnosed with terrible shingles and--

Hughes: Was herpes recognized as one of the diseases associated with AIDS?

Lewis: It came to be recognized. I don't think initially that they realized quite what was happening, but it wasn't long before herpes was accepted as one of the diagnoses.

At the Denver meeting [in June 1982], the diagnoses were a big part of what was being discussed. What diseases were included as part of the diagnosis has been a point of discussion quite often all along. A diagnosis of AIDS determined which people would get services like Social Security, so the diagnosis was really important.

Hughes: You wanted to get new opportunistic diseases on the official CDC list.

¹ August 8, 1983.

Lewis: Yes, the more included, the better, from the perspective of the patient. And yet, once a disease was included, it was stigmatizing in and of itself. So it was--

Hughes: A two-edged sword.

Lewis: Yes, exactly. Tension was a big part of AIDS all along.

Comments on People Living with AIDS

Hughes: Please comment on how people living with AIDS experience and cope with their illnesses.

Lewis: One of the things that's always really struck me about people living with HIV is that, for many of them, it leads into the best time of their lives, in a lot of ways. Many people that I read of and talked with saw it as a time when they got their lives together and took control, and made very productive changes. I've heard of that as being particularly true for a lot of people who had substance use problems, and may have given up for a period of time, and then realized that, no, there's more that they can do to become much more productive citizens.

In the early years, the way people coped was--generous isn't the right word. There were people who were very angry. But for the most part, I saw a great deal of giving, a great deal of spiritualness, not religion--it wasn't that people got religion--but they got in touch with their spiritual self. When they were healthy, they often worked in AIDS organizations. Many of the early workers, both paid and unpaid, at the AIDS Foundation, Shanti, and other organizations, were people living with HIV. And so they gave back a great deal.

They often made efforts to repair bridges that had been broken with their families. Families responded in different ways. Some were terrible, and some were wonderful. But I was always very, very impressed with the way people coped, and how they dealt with this blow that they'd been given. I found it just awe-inspiring many times, that people would be so giving when they had so little energy to give.

Bobbi was certainly a good example of giving until the day he died, and being there for people, and being willing to go out and do presentations and talk about his experiences, and put himself out there. That's real courage. And there were many, many other people like that--Bobby Reynolds, and Dan Turner, and so many

folks. One of the things that kept me engaged in the work for so long was the people who were in it and just my awe of them in many circumstances.

Member, Board of Directors, Kaposi's Sarcoma Research and Education Foundation

[Interview 3: July 10, 1995] ##

Hughes: In 1982, you became a member of the board of directors of the KS Foundation. How did that come about?

Lewis: There was an open call for people who wanted to be on the board, and I applied. Bob Bolan was the president of the board at that time. There was an interview process, and I think they selected me because I was doing community education. The foundation was aware that it needed to do more work in that area, and I felt that I might have something to offer there. The area I was weak in was the board needed to raise money, and I'm not a good money-raiser. I didn't go with the intent of doing a great deal of that, although we had to agree as a board member that we would participate actively in fundraising.

Marc Conant at that point, I think, was already off the board.¹ I don't remember him coming to the meetings that we had, although he was certainly still a player and obviously an influence.

Hughes: That was one of my questions: how involved was he in actuality?

Lewis: My recollection is he was not that involved, although everyone was aware of him. He was doing a lot of national and international speaking and was a public figure. But in terms of the day-to-day work of the board, I don't recall him being at meetings on a regular basis.

Hughes: You said last time that he envisioned the foundation as having a national presence?

Lewis: I know that to be true. Marc had a vision that there would be a national AIDS research and education effort, and that it would be

¹ Conant was president of the foundation board of directors from 1982 to 1984.

the San Francisco AIDS Foundation that would be the major moving force.

The City of San Francisco's Response to the Epidemic

Hughes: Where did Marc and others look in those very early years for the central organization of the city's response? Who was it?

Lewis: I think it would be primarily Merv Silverman. Dianne Feinstein was the mayor, and she was quite responsive. She had a large contingent of gay and lesbian people who had been supportive of her through the years, and so she was very much there for the gay and lesbian community. Then in the health department, of course, you had Merv Silverman. So there was city emphasis on the epidemic, but at the same time, there were lots of other problems in the city. It was not the major problem that it is today; it was a growing problem, but it was still relatively small in the scheme of things for the city.

Hughes: My understanding is that Merv Silverman wasn't particularly engaged in the epidemic until 1983, when the bathhouse episode began.¹ And that, of course, brought him directly in. But as you're saying, before that, AIDS was just another problem in the city.

Lewis: It was just one. It was there in the background, but it wasn't a major issue that the city focused on. The bathhouse episode got into the major papers and was a big deal. There were major news stories on that. They made the whole city aware that AIDS is a problem, and it's a growing problem, and our city needs to deal with it.

Community Social Services for People with AIDS

Lewis: In the real early days of the epidemic, I was trying to hook up with the American Cancer Society or Visiting Nurses Association, trying to find--. As I mentioned, I had been an OB head nurse for a number of years. When a mom went home with a baby, we could send out referrals and get help. When we had people in the hospital who needed care at home, we could refer them to agencies.

¹ See Silverman's oral history in the AIDS physicians series.

I remember making lots of calls, trying to get agencies to incorporate people with HIV into the services they already provided. I really am a strong believer in not reinventing the wheel. If there's already a service provided, why not just add in another group of people?

Hughes: Were the agencies responsive?

Lewis: Not at all. None.

Hughes: Why?

Lewis: In my mind, it was more homophobia and less infection control issues. They would for the most part say the disease was unknown and cite infection control issues. I think it would be real difficult for a public agency to cop to homophobia. But the reality is, when you called and initiated a conversation, those were the two issues you had to bring up right away: "We don't know how this disease is transmitted, and it does seem to be a disease with an infection component, although we think it has to do with sexual transmission."

Hughes: You presented it as a disease of male homosexuals?

Lewis: Yes, that it was gay men that were getting it. And I didn't get any responsiveness at all from any of those agencies.

Hughes: What reasons did they give?

Lewis: Oh, limited funding and that the disease wasn't their mandate. There's a whole litany of things that people can say about those things.

Simón Guzman

Lewis: The piece that I remember first was in relation to Simón Guzman who lived in the East Bay. He was discharged from Moffitt Hospital, UCSF, as I recall, over Christmas of '81. I think he died early in '82, like January or February. But he did go home for a brief period, and I was trying to find community resources. He lived alone, although he had a brother who was also an illegal alien who lived with him or very close by--I think with him. No one in his family knew that he had this disease. They knew he had a disease, but they didn't know that he was gay; they didn't know it was "the gay plague." It was really important to him to keep that secret.

But at the same time, if you were calling VNA [Visiting Nurses Association] or public health or something, to provide support, they had to be made aware. So it was very difficult to find support services for him.

Fear of Infection

Hughes: Now, it was Christmas, 1981. Do you remember thinking that Simón could be infectious, that he might be a danger to you and others?

Lewis: Oh, absolutely.

Hughes: So despite all the other theories about etiology--poppers, immune overload--you were thinking the cause could be an infectious agent?

Lewis: We didn't know. This was around the time that I mentioned to you where I woke up one morning with a fever in the middle of the night and thought, I've got it.

We were conscious and careful about infection control. I would go in Simón's room and sit on his bed and hold his hand, but I would wear an isolation gown. And as soon as I got out, I would wash my hands immediately. Because you didn't know. And shades of grey of not knowing are very hard.

The administrative people in community agencies, who are well educated, all understand that. But the home health aide who goes into the home and actually does the work is the one who is scared to death. She's the one who needs support, who maybe has never known an openly gay person, who has heard about diseases that float through the air, that you touch somebody and you get it.

Hughes: Plus, isn't it true that in some KS cases, patients look pretty awful?

Lewis: Yes, the lesions.

Hughes: Wasn't that particularly true of Simón?

Lewis: Simón did have some bad lesions. So yes, people could look really bad. So you could understand why a community agency wasn't ready to undertake this new challenge.

Chair, Community Education and Support Committee, KS Foundation

An Organizational Meeting, Spring, 1982

Hughes: Well, as of September, 1982, you were chair of the KS Foundation's Community Education and Support Committee, which before had been called the Patient Support Services.¹ Do you remember?

Lewis: Well, what I remember is Marc called me and wanted me to attend a meeting that night or the next day at Everett School over by 18th Street in the Castro. Fliers had been put up in the Castro about an organizing meeting. They were looking for people who wanted to help people who had the disease. He asked me to be there, and so I went.

Hughes: Is that it? [shows announcement of a meeting]

Lewis: No, the meeting that I'm talking about was asking people to help.

Hughes: Appealing particularly to gay men?

Lewis: Yes. It actually sounded more like what Shanti evolved into, where they were giving hands-on help to people with AIDS. [telephone interruption] Cleve Jones and Marc and I and somebody else were sitting up on the stage, and these men started gathering. There were probably fifty guys.

Hughes: What year?

Lewis: That would have probably been in the early spring of '82. It was early. It was before there was an education committee or an active KS Foundation board and services that were community-based. Marc got up there and started talking about the KS Research and Education Foundation. It was going to be for education and research, and I'm having trouble remembering the third arm.

Hughes: Patient support?

Lewis: Yes, patient support. He talked a little about his thoughts about the foundation, and then he said, "And now we're going to divide up into subgroups, and I want you each to pick the topic you're

¹ Committee Meeting Report: Community Education and Support. September 2, 1982. (AIDS History Project Archives, Special Collections, UCSF Library, AIDS/KS Foundation Records, 1982-1986, box 1, folder: Meeting Reports, 8/82, 9/82)

most interested in. You'll meet, and there will be a leader there who will take the meeting to the next step." He turned to Cleve and said, "And you're going to--" I don't know if Cleve took education. Marc took research, of course. And then Marc said, "And Angie will talk about patient support."

I had no notion in the world that he was going to do this. I didn't quite know why I was at this meeting. And do you know, of those fifty guys, probably forty-eight of them went into my group. I mean, they all wanted to do patient support.

Hughes: Because they wanted to help the people they knew.

Lewis: Exactly. If one had been forewarned, one might have been prepared when they all showed up in my corner! [laughter]

Hughes: What did you do with them?

Lewis: I punted. That was the very beginning of the hotline. I can remember Helen and me working on that practically in the middle of the night, trying to answer the phone lines. But at that meeting when all these guys showed up, we just brainstormed about, "What would you like to see happen? Do you have people in your life that you're concerned about who need help? What kinds of help do they need? What's reasonable to expect that we could do? What would be the best thing that could happen if we had all the resources in the world?"

That meeting was the beginning of the AIDS Foundation as it evolved into its current form, although it's gone through thousands of permutations.

Patient Support Services

Hughes: Your group became the foundation's Patient Support Services Committee?

Lewis: The patient support group, and then there was an education group and a research group. But they didn't stay that formally separated, because people served on more than one committee, and the committees overlapped. Like I was interested in education as well as patient support.

I don't quite remember the evolution of Shanti--if there was a patient support group at the AIDS Foundation which duplicated some of the service that Shanti provided.

Hughes: There must have been, because there are minutes of a September, 1982 meeting. The notekeeper, Rick Crane, wrote, "...informal 'coaching'/emotional psychosocial support services provided via drop-in to KSF office."¹ And then there is concern recorded later in the minutes about duplication with Shanti services.

Lewis: So Shanti was already formed by this point.

Hughes: So Shanti must have been formed.²

Lewis: Okay. Because I think the night that we had this other meeting, there was no Shanti, or we did not know of it. It's just very hard to sort of reconstruct this accurately in the time frame.

Hughes: The KS Foundation was founded in April of 1982. That's when Frank Jacobson, Marc Conant, and Richard Keller signed the incorporation papers.³

Lewis: Frank Jacobson was in the room when Marc drew the map of the U.S. And that would have been prior to April of '82, maybe January or February. Frank eventually died of HIV.

Hughes: Was he sick then?

Lewis: No.

Hughes: Did you have a special friendship with him?

Lewis: I had one with Frank and his wife. [tape interruption]

Hughes: What was done about the potential overlap of the services with Shanti?

Lewis: I can remember having lunch with Jim Geary and I think Helen, and talking about the services that they were offering there already. [telephone interruption]

¹ Ibid.

² According to a project flyer, in 1981 "Jim Geary of Shanti Project--a small, already-existing group of volunteers providing support to people with life-threatening illness--[ran] the first support group for gay men diagnosed with [a] mysterious new cancer." (Shanti Project: 1981-1991. A Decade of Caring and Compassion. [n.d.] Author's collection.)

³ Conant's oral history in the AIDS physicians series, pp. 121-122.

Mitch Bart was an important player in all this. He was originally a volunteer who became, I think, acting director of the KS Foundation. He is still in San Francisco, not in AIDS directly anymore. He would have good information about how things evolved.

I was one of the people really concerned about avoiding duplication of service, my same premise of not reinventing the wheel. We had limited resources, and I didn't want us to expend them trying to do something somebody else was doing. But the reality is when you're developing these kinds of organizations, there's a real need for and feeling of ownership because people want their thing their way. So it's difficult, but I think we were pretty good at not overlapping.

It was clear that Shanti was evolving into a primary patient support mechanism, and so we, the board, and those of us in the patient support group per se, felt that it was most important to support Shanti in doing that work. I don't remember the exact people who felt strongly that the foundation needed to have support services for patients. I can remember that being contested, the way things were going to go. The AIDS Foundation did, in fact, develop some support services which they still maintain. What evolved was social support in terms of helping people get Social Security, going through the bureaucratic system, that kind of thing, not direct care services in the home.

When all those men at that meeting came over to my corner, they wanted to put hands on and help people in their homes. And that's what Shanti evolved into, and that was what in my mind was patient support. But as the foundation evolved, it became clear, of course, there were many other needs that people had.

The Foundation's Hotline

Hughes: Well, talk more about the hotline. Were you and Helen initially answering the phones?

Lewis: Well, we only had certain hours. I remember we had an office upstairs on Castro and 18th, the second story. There was one room that we had as the phone answering service, so we had to set up a schedule and get people volunteered and have educational meetings for them. The hotline was answering questions and providing information about services, which were limited.

There weren't a lot of calls initially. I can remember sitting for whole evenings and having no calls. For one thing, it wasn't well advertised. For another thing, there just weren't that many people in the city impacted by the epidemic at that point.

Hughes: When did the calls increase?

Lewis: Oh, as the epidemic expanded, it got busier and busier. One of the reasons that I began to help with the hotline was I had served on the child abuse hotline in Marin when I was working on my master's. I did a year or two working on that line. I'd been through their trainings and had their training guides. I had that information to share with people.

There was only a very short period of time when there were just a few of us who were working on the hotline. Very quickly, there were other people who said, "Oh, I want to help," and pretty soon, somebody else was running the phone line and somebody else was doing the training. The point was to let people grow and take on new things.

Hughes: Were the calls for psychological support as well as for information?

Lewis: Yes. The calls fell into several realms. People who already had HIV, who were already sick, were usually hooked up with Shanti already. They generally got psychological support from their Shanti volunteer so they didn't have a need to call. People who were newly diagnosed would call. A lot of the calls were from people in the community who were just scared, or saw something and were afraid that it might be a KS lesion, or who had heard about this disease that was striking gay men, and what was that about and what caused it?

Of course, we had very little information in early 1982. There wasn't a lot you could say about what caused it, or about transmission. So mostly you would try to calm people and let them know that there was work going on, and there were places where they could help if they wanted to help, in terms of coming to the foundation or Shanti, and that there were people who wanted to help them if they needed help.

There were a lot of things missing at that point in time. The San Francisco model of comprehensive AIDS care was just beginning, so at that point it was basically Shanti and the AIDS Foundation. Shanti was Jim and a few volunteers. Then the AIDS Foundation with the few of us.

The Foundation's Expansion

Lewis: But the AIDS Foundation did grow quite fast. We were in the three rooms on Castro for a little while. Then we moved over to the PG&E [Pacific Gas and Electric] building where we had a much bigger suite, and then we moved over to Valencia [Street], and then finally to where the foundation is now. I remember, in the move to Valencia, the members of the board of directors were so nervous taking on the responsibility of paying all that rent money every month. Where were we going to get it? That was when I was still on the board. The foundation started in Marc's office in a certain sense, but the first official office was on Castro.

The Foundation's Speakers Bureau

Lewis: In terms of education, it started out with Marc, and then I started doing a good bit. Marc did a lot of community presentations. As a physician, he could speak to other physicians with credibility. Nurses didn't have credibility. So he would be the one who would give the talks to physicians.

The Speakers Bureau actually started real early on, probably mid-1982. I was one of the key people who did a lot of speaking locally.

Hughes: Meaning San Francisco?

Lewis: San Francisco and the Bay Area, so it might be the East Bay. I don't remember ever going to Marin. But people would call and say they wanted a speaker, and it was most often educational programs that I did, or educational programs for medical people. It might be at a nursing home--I can't remember actually doing any of those until later on, because they didn't envision themselves as needing it. But hospitals. It was hard to separate what I did as a member of the AIDS Foundation as opposed to doing community outreach for UCSF as a nurse educator.

Hughes: Did you do it differently in each role?

Lewis: No. And, in either case, I would usually be introduced as a nurse educator from UC. I was supported by my boss and Helen and the Department of Nursing Education and Research to do those presentations. That's good PR for the university.

Hughes: It was part of your job, so you were getting paid for some of this?

Lewis: Probably, if it was during work time. I was on a standard schedule; I was on a salary. If I had a class at ten o'clock at PMC [Presbyterian Medical Center] or wherever, I would get paid to go and do that.

Hughes: What about the evening presentations?

Lewis: No, that was all volunteer.

Cleve Jones

Hughes: Do you want to say anything about Cleve Jones?

Lewis: Cleve was a very articulate, bright gentleman. He ran for the [San Francisco] Board of Supervisors a few years ago, and I haven't heard much about him since. He was the person in government whom Marc was connected with, and consequently I was connected with him, too, as part of the board and the foundation.

Cleve came to meetings more than Marc did, but he was very involved in lots of other things. He had been Art Agnos's person in Sacramento. Agnos at that time was in Sacramento, and as I recall, Cleve lived in San Francisco but spent much of his time in Sacramento, as one of Art's primary assistants. So he knew a lot of players statewide and had a lot of very strong connections, so was powerful in that sense. He later went on to do the AIDS Quilt Project, which is an example of how far-sighted he was.

Hughes: He was furthering Conant's aim of money-raising and lobbying at the state level?

Lewis: Yes.

Hughes: He was the principal link with Sacramento?

Lewis: Yes, he was a very strong link with that whole scene in Sacramento: the state and money and power. He had a lot of connectedness with power brokers.

Patricia Norman

Hughes: Well, Randy Shilts says that there was some reluctance on the part of Pat Norman, who was, as you know, director of the health department's Office of Lesbian and Gay Health, to support the foundation's education program.¹ Do you remember anything about that?

Lewis: I don't remember specifically. I've known Pat over the years, although I haven't seen her in many years. I certainly do remember the office of gay and lesbian health, which was probably the first such office in the nation. Pat, as I tend to do at times, tried to "make nice." She's a black woman, lesbian, who's a grandmother now. I remember her as trying not to inflame any part of the mix in San Francisco.

She had been empowered, but only by empowerment that she had created herself, as opposed to gay men, who wanted things to happen now. I think Pat grew a lot through the AIDS epidemic, and later became much more of an outspoken advocate than she was in the early years. That office was real tenuous, and its funding was always a question, and she had to be politically supportive of what was going on in the health department.

Attitudes to People with AIDS

Hughes: Did you respond differently to patients with AIDS than to patients with other problems?

Lewis: I wouldn't say differently. I did feel a certain empathy for them, having been hospitalized as a closeted lesbian in years past. I remembered what it was like to be afraid that somebody would walk in if we were holding hands, or that I'd use the wrong words, and that statements which were too intimate might be overheard. It's terrible to live your life that way, and I remembered what that was like.

If you have an interesting disease and you're hospitalized in a research and education center like UC, you are presented at rounds and many details of your personal life are exposed that would not be exposed if you were in for a more routine disease, or were in a run-of-the-mill community hospital. In the latter

¹ Shilts. And the Band Played On, pp. 122-123.

situations, you could get by and nobody would ever know you were gay.

Hughes: People with AIDS at UC were being exposed in this way in the early days?

Lewis: Yes. I wouldn't say they were all being presented, but the word would get around that people had the diagnosis. It wasn't that it was advertised or that it was presented inappropriately--although I'm sure it was inappropriately presented at times. Someone found that on one of the units there was a list of patients posted who were HIV-positive. I can remember writing a letter to the head of whatever department it was and saying, "This is really inappropriate. You can't be categorizing patients by virtue of their diagnosis."

Hughes: How did patients feel about it?

Lewis: If they were aware, they often felt really bad. But the reality was that they could feel that they were being singled out and stigmatized, but there wasn't a lot they could do about it.

Hughes: Do you think that was the response? Because I can imagine a Bobbi Campbell saying, "This attention is great, not only because I like attention, but also these people are interested in what I have, and maybe they're going to be motivated to investigate the disease."

Lewis: I remember a conversation I had with Bobbi after Marcus presented him at rounds. I stayed afterwards and spoke with him about the experience. I think he was a little uncomfortable; everybody was putting on their gloves and prodding at the lesions--although putting on gloves was appropriate. I would have put on gloves, too, if I were going to prod the lesions. But that makes the patient feel more vulnerable. And here are all these people who walk in in their white coats and their three-piece business suits, and you're sitting there in your skivvies while they look at you in whatever way they want to look.

It wasn't unique to Bobbi or to AIDS, but there often is very little eye contact in that situation. People avert their eyes. It's very dehumanizing. It's a way that medicine is moving away from, and they are often really trying hard to be more personal, before the physician invades a person's space in the way that has been done traditionally.

Reactions of Patients to an AIDS Diagnosis

Hughes: Did most people equate a diagnosis of AIDS with fatality?

Lewis: It's hard for me to answer that, because I wasn't interacting with people at the time that they got the diagnosis. I had friends whom I was very close to that I can speak to, but I can't speak to people more generally. In my experience, people tended to feel it was a death sentence.

We hadn't heard from one of our friends in a long time. He was the kind of guy that we would often see at the Gay Freedom Day Parade, and we wouldn't see him for another year until he was in the parade again. We had first been friends back in the sixties in Florida. He called me one day sort of upset, but didn't mention anything about being sick. I went and picked him up, and he lived with us for three or four weeks. He was down and out and having a hard time. I said, "You've lost weight," and he said, "Oh, yes, I've been dieting really hard." He'd always been a heavy man.

While he was with us, I remember talking with him about this new disease. He was very much South of Market: he was into lots of heavy sex, and S&M [sodomasochism], and all kinds of things. I remember saying to him, "You really need to be careful. You need to, at the very least, wash your hands." And he said, "Angie, where I have sex, there is no water."

He left, and we never heard from him again until Cliff Morrison held him in his arms when he died. I know now he was there at the house saying goodbye, but I didn't know it at the time. I wasn't aware of wasting then and didn't spot it in the way that I would spot it now. I feel certain he knew he was dying, but he wasn't ready to say anything.

Hughes: Helen expressed concern about the sexual history that was going into patient records, because many people have access to them.¹

Lewis: Practically anybody who wants to pick them up, or at least in those days.

¹ See Schietinger's oral history in this series.

Patient Charts: Confidentiality Issues

Hughes: Was patient confidentiality a concern to you?

Lewis: Confidentiality was a concern to all of us a lot of the time. In those early days, there was some sense that you could judge something about this disease by virtue of the number of sexual partners one had had, or the type of sexual practices. Or that research would glean something from this. If people did certain things, that they would get it, or if they avoided certain things, they wouldn't.

I can remember going to a meeting, Mike Gorman was there, and the Englishman--

Hughes: Andrew Moss.

Lewis: Okay, it was Andy's study. Gorman was his first assistant. Andy used to come to these little meetings--

Hughes: The KS Study Group?

Lewis: Yes, he was part of that. So that's where I met him. He was going to do a study about sexual histories. I dragged Shirley along. We were both going to do interviews with patients, and we did do some. There was some feeling that there were answers there somewhere in the sexual histories. Andy composed a thirty-page questionnaire. It went into everything in your whole life that you'd ever done. I can remember they were looking at things like swimming in the Russian River; they were looking anywhere and everywhere for what have these people done?

Andy was doing a research study, so people were coded and it was confidential. But the fact is in those days, because we didn't know the etiology, people collected a lot of information about sexual history that is not collected much anymore. If you or I go to the doctor, he doesn't ask much of anything about our sexual history. There might be a general question on a checklist about sexual impotence, but nobody asks the details of what we do in the bedroom.

People began to ask those kinds of details, and they didn't have a format, so they would write notes that would just go on and on. You can imagine how interesting people found it to look at. If you're a medical student and you're assigned to X ward, and there is one of these patients there, don't you think you might find a way to read that chart? Yes, you do. And that happened a lot.

Now, eventually--primarily related to the confidentiality of HIV antibody test results--a separate section of the chart was kept. That had to have been after '85. In the days that we're talking about, there was no thought of a separate chart. That wasn't anything any of us had a concept of. So all that very private, very detailed information was kept in the patient chart. Now, there would be some patients where the doctors weren't as aware or didn't have the interest or didn't feel it was important, where there wouldn't be much sexual history recorded. But then there were other times when interviewers got very involved, particularly with individuals who had had 500 or 1,000 or many thousands of sexual partners. They would get into very detailed histories, and sometimes the patients just wanted to talk about it.

It was an issue, because there wasn't a way to keep the information confidential. And I don't know that patients, when they tell one health care provider something, have any awareness that this information has the potential to go far beyond that individual.

Hughes: You don't recall anything concrete being done to increase the security of this information?

Lewis: No. To the best of my knowledge, nothing was done at that point in time. Once the test results started to be known, the concept of a private chart evolved.

Networking

Hughes: It's important to record how information was exchanged.

Lewis: Networking was very important. As each organization evolved, people developed a sense of ownership of a part of the epidemic, and a guarding of that. And then before too long, people had jobs or were invested in other ways in the epidemic. I thought it was really important to avoid duplication and to interlink people. One of the things I tried to do a lot was to connect people together, because I really do believe strongly that no one organization is going to solve all the problems or knows everything.

The people who were significantly involved in HIV organization and education were a small enough group, as I've mentioned, that in the early years, at least the first six months or a year, I knew damn near everybody who was involved in San

Francisco. And I knew some of the patients, mostly some of the UC patients, but not anywhere near all of them. But the ones who were politically active I knew, the ones who were going to meetings. I didn't know the ones who were home sick.

I met persons living with HIV at the meetings, and they were the people that I called to be on panels. When I would do educational programs, whether for the board or for UC, I would always try and take at least one person living with HIV with me, because I'd rather have them talk for forty minutes than for me to stand up and do a didactic for an hour. The audience needs to get a sense of the humanness of the disease.

I think networking was really important in it--in San Francisco and nationally, where it was important to connect with community people across the country, and with Jim Curran and the folks that were at the National Institutes of Health.

More on the KS Study Group

Hughes: Was the KS Clinic and Study Group the coordinating center for the early medical response to the San Francisco epidemic?

Lewis: We talked earlier about how at the first meeting I went to of the KS Study Group, there were maybe eight or ten people. Within a year, there were probably forty people, maybe fifty or sixty at a good meeting. There were periods of time when Marc would come out with an agenda and you'd know what the topic was going to be. There were other periods when there was no pre-announced topic because Marc didn't have any support to do the secretarial work.

Hughes: His office staff did it sometimes?

Lewis: If they had the opportunity, they did it, but then there were lots of times when they couldn't. So it was on-again, off-again.

That meeting was attended by the medical people from the university, the community, and the health department. It began to be attended by folks from the AIDS Foundation and Shanti and many of the community groups. I made a point of trying to get to the study group, because it was where I connected with people and was able to say, "Hey, what about this? What about that? Can you do this?"

Hughes: So there was time for informal exchange?

Lewis: Yes, at the end of the meeting, after the more formal program was over.

Hughes: The meetings consisted of formal presentations?

Lewis: Generally, there was a speaker. There was an opportunity for anybody to make an announcement. So people would say, "Oh, we're having an educational program this date and time--"

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Hughes: I heard that as time went on, there wasn't a need to continue patient presentations. People knew how to identify KS.

Lewis: Right. Instead, it might be Jay Levy talking about what his latest research was. Sometimes we'd get a speaker from the East Coast who was in to do rounds for the department of immunology or something. Marc would often have him come over and do a presentation for the study group, which would be a lot more intimate than what rounds would be, where there were several hundred people. An outside speaker could meet with a lot of the key players in AIDS research at one time and location.

So the presentations moved away from patient presentations fairly early, and got into much more research-dominated topics. I can remember talks where I practically fell asleep, because it was so "out there" for me personally. I just didn't have the knowledge base to comprehend some of them.

Hughes: So it was hard-core medical science?

Lewis: Oh, yes, at times.

Hughes: Because all these people representing different pieces of the AIDS pie met in one place at the study group, wasn't it a chance to organize?

Lewis: Yes, although the organization was more often around educational issues than it was around political issues.

Hughes: Was there any other occasion like that in those early years?

Lewis: No, not in the really early years; there was nothing else. That was the one place and time a week that everybody interested in AIDS came together. It was the opportunity each of us had to talk with each other. Because there was this open period for announcements, you could say what you wanted to say. Also, there were times when Marc would have presentations by local organizations that were providing services or whatever.

I'm having trouble in terms of the time frame--what time things moved into more formal presentations. I'm sure it was within the first year or year and a half that we moved out of patient presentations.

Patient Zero

Lewis: We heard all about Patient Zero when it was still on the drawing boards.¹ I remember when Selma [Dritz] and folks from public health were psyching this out. I think Mike Gorman was also real involved in that one. We heard about it as it was happening, at these study group meetings.

Hughes: Pretty exciting.

Historical Importance

Lewis: You had the sense of, I'm in the middle of history.

Hughes: Even then, you did?

Lewis: Oh, yes, absolutely. You just felt, This is a once-in-a-lifetime thing, and I'll never experience this again. You just knew that what was happening was really important and would affect the world.

Hughes: What was making you feel that way?

Lewis: The epidemic was just growing so fast, and the numbers were growing so fast. We all had hopes that they would be able to find the virus, and once they did that, that then we'd have a vaccine, and this would be over.

¹ According to Shilts, Patient Zero was Gaetan Dugas, a Canadian airline steward whom Shilts proposed might have initiated the AIDS epidemic in North America. The idea has been discredited. (Shilts. And the Band Played On, p.459.)

Hughes: Was that the assumption: find the virus and the vaccine is the easy next step?

Lewis: Yes.

Hughes: Nobody thought making the vaccine was going to be a problem?

Lewis: I don't know. I had never been involved in a vaccine being made. I grew up in an era, as a nurse, as a human being, where doctors somehow could figure things out, although reality doesn't necessarily prove that out. I think because of my history and my age that I had this trust that this problem will be solved.

You did have a sense of living in history. I really remember feeling, even quite early on, that this disease is bigger than all of us.

Coordinating the KS Clinic and AIDS Activities at San Francisco General

Hughes: What happened when AIDS activities really began to take off at San Francisco General?

Lewis: They would come over to various meetings. I think we changed the day of the KS Study Group to coordinate with their schedules. I don't remember if it started on Tuesday and ended up on Wednesday or vice versa.

Hughes: The clinic met on Thursday morning from nine to eleven, and then the study group immediately followed it. It was dermatology space.

Lewis: Yes, it was in dermatology space; I remember that. In the early years, the clinic was earlier. It was at nine. I know that the clinic was manipulated vis-a-vis what was happening on [Ward] 86 [the AIDS Clinic at SFGH], because routinely, not the nurses, but Paul [Volberding] and Donald [Abrams] and Connie [Wofsy] would come over. They were the three from General who most often would attend the meetings. As Paul became more and more nationally and internationally prominent--and that was after '84--the meetings changed as Paul was no longer able to participate very often. He would come once a month or when his calendar allowed. He would share things that were going on nationally, and this is what he'd done over at Bethesda--

Hughes: So the meeting had a larger perspective when he came?

Lewis: Yes.

Hughes: Well, one thing that was giving him perspective, and that started fairly early, was the drug trials. Do you remember there was an alpha interferon trial that began as early as 1982?

Lewis: Yes, '82.

Hughes: He tells some funny stories about having to deal with the NIH committee.¹ Here was this green physician--

Lewis: Yes, he was. He was right out of his residency, and so was Donald.

Rivalry between Conant and Volberding

Hughes: The only one with any seniority was Conant.

Lewis: Yes. And Conant is the one who lost out.

Hughes: Why?

Lewis: I never have known. Well, for one thing, they were oncologists, so they had a broader perspective of disease than Marcus did. And yet, KS was a major piece of this in the early years, and it could have gone the other way. It could have become more focused on KS, at least for a while, than it did. That's part of what Marc talked about at Langley Porter that day, although he, of course, didn't speak directly of Paul or Donald. He's not going to do that; he's got more class. But there were things that went on.

Now, whether it was that Marcus didn't want to move, that he was fighting to keep AIDS activities at UC on the hill--²

Hughes: I know he was.

Lewis: Yes, he wanted that, I'm sure.

Hughes: Yes. I don't know whether he was invited or, if invited, he would have gone to San Francisco General.

¹ See Volberding's oral history in the AIDS physicians series.

² The main UCSF campus is built on the slopes of Mt. Sutro.

Lewis: I have no idea. My sense is he's used to having a nice office space, and he wouldn't fit at General at all. General is a scroungy space. There is nothing accommodating to providers--it's a county hospital. UC is a university research center. They are worlds apart in many, many ways, part of it being the very patients who go there. Marc had a practice at UC established long before AIDS and a large group of patients who would have been mortified to go to General. They were not going to go down there.

And the kinds of patients he attracted in the HIV epidemic were similar patients. They tended to be well educated, well moneyed, empowered. Now, they happened to be gay men, but they could have easily been matrons from a fancy neighborhood. So it would have been, in my mind, unthinkable for Marcus to pick up things and move to General. I think that would have been saying--

Hughes: Donald started at UCSF and moved over to San Francisco General. Volberding was always at San Francisco General, in terms of his position as head of the Division of Oncology, although--

Lewis: He had done his residency at UC, hadn't he?

Hughes: Not his residency, but a fellowship. Why were they willing to work at a county hospital?

Lewis: Well, think about it a little. Paul was young. He was new at his practice. He wasn't established. He didn't have well-known credentials, where Marc had national connections in the dermatology field. The General is a kind of high-power, high-energy place that young physicians often enjoy. They feel altruistic. You give a lot of yourself; you put in incredible hours. His wife, Molly [Cooke], was over there.

When I was a young nurse, I wanted to be in a big hospital. I wanted to be in a county hospital. I wanted to give to people. As you mature and as your practice grows, your focus changes. Marc had already gone through that early time in his life, and would, I think, have had no interest in going to General. Now, I don't know any of that to be a fact. It's just my assumption. I can see that it would be very exciting for Paul. He was a young physician. He got the opportunity to be head of oncology for a county hospital in one of the major metropolitan areas in the United States. It was very prestigious, I would assume, to have that position. And then all that evolved afterwards, of course, far exceeded his expectation. I've heard him and Molly talk about that at different times. They had no idea what life was going to hold for them.

Potential Career Risks

Hughes: Did the physicians involved with the epidemic in the early years feel that they were taking a risk in terms of their own careers? It could have been for many reasons. First, it was a stigmatized disease--

Lewis: That's it. That's the major thing. When you had a physician come speak, there would be some mention within the first three minutes of his wife and children.

Hughes: "I'm not one of them."

Lewis: Exactly. They did a great deal of distancing of themselves. It would be worked in very casually--

Hughes: But the point was there.

Lewis: Yes. So I think that piece they saw as potentially damaging.

I think they felt they were taking a certain risk with their careers. There were only a few where it could have had that impact: Paul and Donald and Connie are the three that come to my mind within the UC or the General family. But I never heard them really articulate that fear. I think they all felt that the work they were doing was really important and needed to be done, and I didn't get a sense of their holding back or of being concerned about their careers. They were young, and young physicians have to look at their careers, particularly if they're academics.

Staff Commitment

Hughes: Did they have a sense of idealism: they were in this because it was an important humane thing to do?

Lewis: Yes. I think they all did. I always had a very positive feeling for the physicians and for the work that they did. I just finished working on Ward 86 for four years; I left in January [1995]. I was constantly in awe of not just physicians but the care providers, the nurses, the people who were at the reception desk--everybody, I felt, was really there for the right reasons and gave a lot. And it is getting harder, in this day and age, as more and more patients are substance users and have very difficult histories that made them less amenable.

In the early days, people who were the patients, '81 to '84, for the most part looked a lot like the care providers, and had the same life history. So there was a sense of connectedness, even though Paul was straight and they were gay. That's not true these days. I have great respect and regard for all the providers there. I think particularly Paul and Don and Connie just were incredible over the years.

Dealing with Informed Patients

Hughes: Well, you mentioned being a bit intimidated by well-informed patients, and that hard-core science was not something that you were responsible for. What did this do to your relationship with patients?

Lewis: Oh, a lot, I think. Certainly through mid-'82, maybe late '82, you could reasonably aspire to have read every AIDS-related article that had been published. And I read along with everyone. There were no books but there was a lot of background information. There was a lot of immunology; there was a lot of epidemiology; there was a lot of information that wasn't specific to AIDS that theoretically physicians already had that patients didn't have. So a patient aspiring to become informed had a wealth of information that he needed to assimilate.

But in terms of information specific to AIDS, it was very reasonable that patients and providers had read the same things. It must have been through the Research and Education group [of the KS Foundation] that there was a bibliography on AIDS put out--

Hughes: Right, there was.

Lewis: So, we all kept up with that. And there was the MMWR, so you subscribed to that.

Hughes: And patients did?

Lewis: Oh, yes. Anybody could subscribe. For many patients, AIDS wasn't just their Monday through Friday eight to five life; it was their twenty-four hour a day, seven day a week life. So when they weren't down at UC library reading, or reading their own publications that they got at home, they were at the AIDS Foundation volunteering, or they were over at a neighbor's taking care of him, or they were over at General at their doctors' appointments, or they were over to see Marc at the KS Clinic and

participate in a research study. This was their life, totally and completely. They had nothing else outside of it.

Paul and Don and Connie were immersed in it, but at least they had some outside life. Paul had his wife and kids, and Donald had a partner, and Connie had her family. So yes, they were immersed in it, but they did go home. I think it was hardest on Donald, since he was a gay man and had many friends who were ill. The patients could become obsessive about it. They could really wear you down. But for the most part, they recognized that providers needed to take care of themselves some.

What was provided for physicians to keep them informed was the KS Clinic and the study group, the KS Foundation bibliography and the MMWR, and they had a lot of connectedness among themselves when they needed to. But the information just got more and more massive.

Alternative Treatments

Lewis: The other piece that began to happen, as it does in any disease, I guess, is that there began to be a lot of alternative treatments. People were into macrobiotic diets or meditation, Louise Hayes, all of that kind of thing. That was an area where I think most physicians were less well equipped to deal with and less informed. Patients would come in claiming to have heard that this was going to do X, Y, or Z--raise your T cells or whatever. That was followed in the BAR and the Sentinel and those kinds of publications.

Actually, at UC or at [Wards] 86 and 5A, those kinds of places, they always had those gay press papers around and made a point of having them there for people to look at. It was very common to see providers looking through them and trying to keep up, because that was the piece where I think they felt unequipped.

Hughes: Physicians were being asked by their patients for advice about alternative therapies?

Lewis: Yes, exactly, on things that had appeared in the gay press, but that had not appeared in the mainstream literature.

Hughes: Did you have to deal with alternative therapy?

Lewis: Oh, yes.

Hughes: How did you handle it?

Lewis: I'm pretty supportive of alternative therapies, and really believe that people ought to investigate and try what feels right for them. I don't see a conflict necessarily between traditional and alternative therapies, and I think that they can work together. I think a lot of what happens in health is in your head, and if you believe in something, if you really have faith in it, that you should try it.

I've always been pretty open to it. Well, I'd been in OB for years. I'd worked with La Leche League and with women doing alternative birth, and I had worked a lot in trying to empower women in the birth experience. Well, that was a good corollary for helping empower people with HIV in terms of their disease process, and provided me some experience in dealing with that.

Hughes: It's amazing how your past experience was so helpful.

Lewis: Yes, it's really fascinating.

The Epidemic's Impact on Physicians

Hughes: Well, let's talk about the impact of the epidemic on physicians. Maybe start with your perceptions of what the epidemic has meant in terms of authority. Do you see changes there in terms of the patient, the physician, decision-making, knowledge?

Lewis: In terms of authority: that's an interesting question. I haven't thought of it in that terminology. I think there have been major changes, and I think HIV has helped empower patients. The only patients that I really was aware of as exercising their own power previously were certain breast cancer patients who had worked through the American Cancer Society. I had been to a couple of programs on colostomy management that had had patient involvement. And, of course, in birthing, particularly with the home birth movement, women and their partners were active participants and were making personal choices.

I had to do an externship when I was in my baccalaureate program, and I did it with a home birth program in Seattle. There was only a physician consultant, and all of the work was done by lay midwives. We actually set it up so that the lay midwives could go to UW [University of Washington] and get experience there in the delivery room.

So I had been in life experiences where patients were very empowered, and this was no conflict for me to be dealing with patients who felt themselves to be empowered or wanted to empower themselves. It was not necessarily true for most providers.

Hughes: Was that threatening to them?

Lewis: One of the reasons people traditionally had become physicians was that they wanted to have a certain sense of power. It was rarely articulated as one of the reasons one does it, but I think that control and power are part and parcel of the role.

I think that as HIV came about, people who had previously been executive vice presidents of various and sundry corporations in the financial district were getting sick and were very much used to being in control, being in power, and making their own decisions, and they weren't about to sit back and wait. And that was threatening to providers to a certain degree. I think the smart ones got over it really fast. For one thing, these same men were often in their social circles, and so they were peers in a certain sense, although they weren't all academicians.

But it was certainly different for physicians, because their patients, over whom they had control, in the past tended to be older, people toward the end of their lives. We all have to face that we're all going to die, and so there is nothing particularly threatening about that. People haven't felt the need in the past to take control of their dying in the way that they are now. So physicians could be peers or colleagues or whatever and still have that power and authority over people at the end of their lives.

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Lewis: Patients felt a need to control many aspects of their disease process and got into very complex decision-making trees about the kind of medication and when it should be started and what the dosages should be. Most physicians had never envisioned a patient having that kind of interest or knowledge.

So I can imagine it would have been threatening to physicians. It wasn't something that I heard them talking about. The reality is, our roles are such that physicians are not going to talk to me about it. Some, like Donald, became very much a proponent of holistic medicine and alternative therapies, and now he does lectures all over the world on that topic. So physicians' view of the world changed over because of their experience with the epidemic.

John Stansell, AIDS physician at SFGH, is a good example. Having lived through the death of his partner, he developed views about assisted suicide and the dying process, and what the role of the provider is in that. All of them--all of us--had our lives fundamentally changed.

The Epidemic's Impact on Nursing

Hughes: Please comment on what the epidemic has meant to nursing.

Lewis: I think the epidemic has given nursing great opportunities in that there haven't been answers, there is no cure, and it's a disease of caring. It's not a disease of curing at this point. And nurses are good at caring. That's what patients look to nurses for. I found that for the person living with HIV, it was nursing very often that was part of the key. So I think nurses have been empowered by virtue of the epidemic.

I think the nursing profession will be enlarged by virtue of people coming into the profession because of their experience with loved ones or friends with HIV. There's a program at UC [NP] for people who have a degree in some field and are moving into nursing. It's a second-step kind of program, and you can come in with a degree in fine arts and get a master's in three years. Of thirty-three or thirty-five people that were accepted in the program the last year I was there [1994], three of them, I believe, came in specifically because they had been impacted by AIDS and wanted to devote their lives to caring for people who were living with the disease. That's a relatively new phenomenon.

The other thing is that health care is moving out of hospitals and into homes. Hospice is a tremendously growing area of health care, and that's a nursing-dominated piece. That used to be in hospitals or in separate facilities of some kind, but now in America for the most part, it's done in the home. Actual hour-to-hour care is provided by the family or by a helper of some kind. That helper, a certified nursing assistant [CNA], is trained by nurses.

The Inpatient Unit at San Francisco General

Hughes: It seems to me in regard to 5B that nursing played a particularly instrumental role. Look who organized it--

Lewis: Cliff [Morrison].

Hughes: How usual was it to have a nurse organize an inpatient unit?

Lewis: Very unusual. That was a totally new model that combined a number of elements from past models and some that were completely new. I think an interview with him, or extensive readings of his writings, is really crucial, because he did so many things that were innovative. I think we spoke of some of those last time-- support groups and team work where everybody, including the housekeeper, was included. Doing rituals is something that's evolved as part of AIDS care, in terms of a unit recognizing the deaths that have occurred over the past month or whatever, and having a way to honor that and let it go.

All of the people who worked there were volunteers who were there by choice. They have almost no turnover. I don't think they lost a nurse for four years or something like that. It was incredible, just incredible.

Hughes: And it was not easy work.

Lewis: No, oh, it was very tough. It's getting tougher because AIDS units are facing the same strains and stresses that all health care facilities are facing, and the patients are so much sicker and in the hospital for very brief periods of time when they are incredibly ill.

Hughes: The unit [5B-5A] is and was a nursing unit, which was originated by nurses in the schema that you've been describing. Has that happened elsewhere, either in connection with AIDS or not?

Lewis: No.

Hughes: Why did it happen in AIDS at San Francisco General? The unit could have been planned by the hospital administration, or by a group of physicians, or whatever.

Lewis: Right.

Hughes: But it was never that way.

Lewis: No. I'm not exactly sure of the mechanism within San Francisco General that allowed that to happen. I wasn't privy to that. I know that at Flo Stroud's meetings, where the unit was being planned, that Cliff was very purposefully chosen. He was already a head nurse at General, and was known as a leader, and had been very powerful and effective in the positions that he'd had.

I remember being just a little jealous, thinking, "Oh, that would be a neat job. I'd really like to run that unit." [laughs] But I wasn't a General person. They didn't do an external search; it was internal.

Hughes: You would have applied if they had?

Lewis: Oh, I don't know if I would really have done it. But there were times when I regretted not being part of the actual formal organization of AIDS providers.

I remember hearing about the KS job that Helen had with Marc, and thinking, "Oh, that would be interesting." Shirley and I discussed it and she pointed out that you can't work twenty-four hours a day. I could take the job, but then I couldn't volunteer all night. Which I think was good advice.

At any rate, Cliff was chosen purposefully by the administration. I don't know how it evolved that he had the autonomy to organize the unit in the way he wanted it. I think the unit was under certain pressures from the community. For one thing, there had been a lot of discussion about should this be a separate unit. That was part of the meetings that Flo Stroud ran. Paul would usually come to those meetings and discuss where the unit should be going and what it should look like.

Burnout

Hughes: You told me off tape that you were initially reluctant to do this oral history and that, in looking back, you realized that at the end of your career at UC you were suffering burnout.

Lewis: I was, and I am still recovering. I have found over the years that my affect became much flatter; I don't laugh as easily; I don't cry as easily. I feel like I've, in a sense, lost the ability to enjoy life in the way that I used to have. And part of that, of course, is I'm ten years older.

I think the experiences that I've lived through explain why that's happened. I've really pretty much totally backed out of HIV, and at this point have no direct connection with even the local AIDS organizations. I feel like I need to get more centered and learn better how to enjoy myself. I think that that's not uncommon among people who have worked in HIV for a long time. The same applies to people who work in ICUs [intensive care units] for extended periods, or in any kind of really intense interpersonal

experience. I don't feel that I'm healthy yet. I'm not recovered.

Hughes: Well, it was a long epidemic for you.

Lewis: I've only been out of it for six months, not very long.

Hughes: Is there anything that could have helped you or anybody else?

Lewis: I don't know, and I've not pondered that question, because I've only come to accept in the very recent past--weeks, days maybe--the fact that I have had burnout. And so I haven't thought that piece through. I have thought, What can I learn from this experience with HIV, and is there a presentation I should develop and take out to conferences? [laughter] But I don't think I have any of the answers. Right now, I am just giving myself time to heal.

Hughes: That's wonderful.

Personal Contribution to the Epidemic

Hughes: In closing, what do you consider to be your biggest contribution to the HIV effort?

Lewis: I think it had to do with connecting people with each other, as in organizing an educational program, trying to involve the experts, whether it was the book or a formal program or whatever. So a lot of people got to connect and meet each other and learn from each other that would not have had I not done that. The epidemic was an incredible growth opportunity in lots of ways for many of us. There are any number of folks who have traveled the world in ways that they would never in their lives have experienced had there not been the epidemic.

I went to Istanbul, sent over by the World Health Organization to represent American nurses at a meeting on professional education [1990]. Helen actually helped to orchestrate that. I edited a book that was well accepted and read throughout the country. I gave speeches all over the country. So in many, many ways, the epidemic enriched my life. It also impoverished me in certain ways. I think I gave back a good bit, compared to what I got.

Hughes: Thank you very much.

Transcribed by Shannon Page
Final Typed by Julia Rechter

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APPENDICES--The AIDS Epidemic in San Francisco: The Response of the
Nursing Profession, 1981-1984, Volume II

Curriculum Vitae, Gary Stephen Carr, R.N., Ph.D., F.N.P.-C. 172

Carr materials

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Project, Special Collections, UCSF Library, Ward 86, C4, f:
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career prospects, August 10, 1983. (Angie Lewis, private
papers). 185

Health Pioneering in the '80's, pamphlet for The Fifth National
Lesbian/Gay Health Conference, 1983 (Angie Lewis, private
papers). 187

Acceptance letter for and description of AIDS 101: Basic Medical
and Epidemiological Overview of AIDS, a course Lewis gave at The
Fifth National Lesbian/Gay Health Conference, 1983 (Angie Lewis,
private papers). 190

Lewis, memo to Marilyn Chow explaining Lewis's role in and

contribution to AIDS work and education, 1989 (Angie Lewis, private papers).

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Program, American Nurses' Association, 54th convention, 1984, including *Acquired Immune Deficiency Syndrome: Nursing's Responsibility*, a presentation by Angie Lewis and Bobbi Campbell (Angie Lewis, private papers).

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CURRICULUM VITAE

Gary Stephen Carr, RN MS FNP-C

Home address:

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San Francisco, Ca. 94122

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995 Potrero Avenue
San Francisco, Ca. 94110

Office phone: 415-476-0828

Office Fax: 415-476-8881

Voice mail: 415-476-4082, ext. 82231

EDUCATION

1970	State University of New York at Albany, Albany, New York	BA, English
1978	Long Island University Brooklyn, New York	BSN
1982	State University of New York at Stony Brook Stony Brook, New York	MS, Nursing (Family Nurse Practitioner)
1990	University of California, San Francisco	Ph D student

EXPERIENCE

September, 1988 to present: Supervising Nurse Practitioner, AIDS outpatient clinic, San Francisco General Hospital. Administrative and clinical supervision of staff nurse practitioners as well as full clinical practice.

December, 1983 to September, 1988: Nurse Practitioner, AIDS outpatient clinic, San Francisco General Hospital. Primary care clinic, monitoring of patients in clinical trials, screening clinic, liaison with community service agencies and other hospital units, author of AIDS clinic nurse practitioner protocols.

1/81-8/82: Staff nurse, San Francisco General Hospital, Trauma-surgery.

1980-81: Per diem staff nurse, Bellevue Hospital, New York, N.Y., Trauma-surgery.

1978-80: Mount Sinai Hospital, New York, N.Y. Surgical staff nurse: orthopedics, trauma, care of hemophiliac patients undergoing surgery, including infusion of clotting factors.

PROFESSIONAL ACTIVITIES

1975,76: American Public Health Association, including attendance of national conventions. Lesbian/Gay Caucus.

1979,80: Medical-Nursing Procedures Committee, Mount Sinai Hospital.

1978-present: National Coalition of Gay STD Services.

1980, 84, 86, 87, 89 92: National Lesbian and Gay Health Conference attendance.

1985,86,88,90,92: International AIDS Conference attendance.

1987-92: Faculty, AIDS Provider Experience course, San Francisco General Hospital.

1989 to present: Association of Nurses in AIDS Care (ANAC) member.

1989-1993: California Nurses Association HIV Task Force member. Committee Chair, 1991-1993 biennium.

COMMUNITY SERVICE

1974-80: Board of Directors, St. Marks Community Clinic, New York, N.Y.

1982-84: Volunteer nurse practitioner, Haight-Ashbury Free Medical Clinic, San Francisco, Ca.

1993-present: member, AIDS Project Advisory Committee, San Francisco Jewish Family and Children's Services.

AWARD

Award of Achievement, Society for Technical Communication, May, 1987

PUBLICATIONS

Carr G, William DC, Anal Warts in a population of gay men in New York City. Sexually-Transmitted Diseases, vol. 4, No. 2, April-June, 1977.

Volberding PA, Abrams DI, Kaplan L, Conant M, Carr G. Therapy of AIDS-Related Kaposi's Sarcoma (KS) with ICRF-159. Proc Am Soc Clin Onc 4:5

Carr G, Gee G, AIDS and AIDS-Related Conditions: Screening for populations at risk. Nurse Practitioner, vol. 11, no. 10, October, 1986.

Chapters, "AIDS-Related Complex" and "Mycobacterial Infections in AIDS", in AIDS: Concepts in Nursing Practice, ed. Gee, Williams and Wilkins, 1988.

Chapter, "Medical Treatment of Persons with AIDS and ARC" in Nursing Care of the Person with AIDS/ARC, ed. Lewis, Aspen Publications, 1988.

Carr, G. S. Opportunistic Infections and Pharmacology. In, Miramontes, H., (ed.), Management of AIDS in a Critical Care Environment, Critical Care Nursing Clinics of North America. vol. 4, no. 3. September, 1992.

Carr, G. On-the-job exposure to HIV: Reducing nurses' risk. Part 1: California Nurse, vol. 89, (7), July/Aug., 1993. Part 2: California Nurse, vol. 89, (8), Sept., 1993.

POSTERS

1985: Nurse Screening Clinic, San Francisco General Hospital. Presented at International AIDS Conference, Atlanta, Ga., June, 1985.

1987: Nurse Practitioner Role, San Francisco General Hospital. Presented at International AIDS Conference, Washington, D.C., June, 1987.

1988: Nurse Screening Clinic Evaluation Study. Presented at International Conference on AIDS, Stockholm, Sweden, June, 1988.

1992: Western Institute of Nursing, Seattle WA., Ethnography of an HIV Hotel.

AIDS History Project,
Special Collections, UCSF Library
Ward 86, C4, f: Letters for
Abrams, 1984.

San Francisco General Hospital
Medical Center

November 29, 1984

Mathilde Krim, M.D.
Memorial Sloan Kettering Cancer Center
1250 First Avenue
New York, N.Y. 10021

Dear Dr. Krim:

It was brought to my attention by Dr. Donald Abrams that during your recent visit with us at San Francisco General, you asked him about the differences between nurse practitioners and physicians' assistants. At Dr. Abrams request, please allow me to attempt to answer your question.

At the AIDS Clinic, there are three nurse practitioners including myself. We provide primary care to AIDS outpatients during clinic visits. We practice under the guidelines I have enclosed and under the direction of clinic physicians. Administratively, we are members of the nursing staff.

While nurse practitioners and physicians' assistants function on similar levels in many medical practices, there are differences in licensure status, education level, and often in previous background. I don't mean to maximize these differences or take a combative status toward my PA colleagues, merely to point the differences out.

Disease case finding, patient assessment, observation of deviations from expected presentations, and implementation and evaluation of treatments are universally recognized as nursing functions. Therefore, it is my opinion that everything we do except diagnose disease and prescribe medications is covered by our licenses as Registered Nurses. Admittedly, because we do physical exams and order laboratory and noninvasive diagnostic tests, this is not a traditional nursing level of functioning, but those activities are covered by our training beyond basic nursing education and the protocols of our institution. Because physicians' assistants do not have licensure to function independently, they must work at all times under the supervision of individual physician-preceptors. In California, that relationship must be formally recognized by the state licensing authority. We, as Registered Nurses, do not need that formal link to a single doctor, although of course we work very closely with our physicians.

In addition, the present state of nursing education is such that nurse practitioners are schooled at a graduate level in universities. Therefore, in general, NP education now contains more content in research, administration, teaching, and other areas in which nurses function. PA programs are on a bachelors degree level and, as I understand, do not address these other areas as fully.

Page 2

I would like to add that personally, I find AIDS work very demanding of judgement, interpersonal skills, and sensitivity, as I am sure you know. For me, these are skills I have never been fully taught in school but for which I am able to rely heavily and consistently on my experience as a hospital nurse before becoming a nurse practitioner.

Thank you for your interest in the roles of the staff at our clinic, and also for your important work in this tragic epidemic. I hope your visit with us in San Francisco was profitable and pleasant, and we look forward to further communication with our colleagues in New York on every level of AIDS work.

Gary Carr, R.N.M.S.
Nurse Practitioner/AIDS Clinic
San Francisco General Hospital

GC:dwb

City and County of San Francisco



177
AIDS Health Project,
Special Collections, UCSF
Library, Ward 86, C5, f:
Nurse Practitioner Protocols -
changes 1985/86,

Department of
Public Health

San Francisco General Hospital
Medical Center

Oct. 30, 1985

*Process Protocol for Nurse
Practitioners*

*Ward 86 AIDS Clinic
SFGH*

Encl. 10/85

To: Drs. Volberding, Wofsy, Abrams

From: Gary Carr

It is time for the annual review of the nurse practitioner protocols. They appear different due to format revisions to conform with protocols of other clinics in the hospital, but the clinical content is basically unchanged.

Please do not sign the enclosed copy which is for you to keep; I will approach each of you in the near future for your comments and signatures on the original copy, which I'll then forward to the Inter-disciplinary Practice Committee.

Thank you.

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University of California, San Francisco
CURRICULUM VITAE
(abridged to reflect AIDS focus)

Name: Carole Angie Lewis

Prepared: 10/91

Current title & department: Clinical Research Nurse
Community Consortium
University of California, San Francisco

EDUCATION:

<u>Dates</u>	<u>Institution & location</u>	<u>Degree Conferred</u>	<u>Major subject</u>
1962-65	Charity Hospital School of Nursing, New Orleans, LA	Diploma	Nursing
1971-73	Univ. of Wash. Seattle, WA	B.S.N.	Nursing
1976-79	Univ. of Calif. San Francisco	M.S.	Perinatal Nsg.

LICENSES and CERTIFICATIONS:

1973-now Registered Nurse, California
1987-now Certified AIDS Educator, California Nurses Association
1989-now Certified WEDGE Educator, San Francisco Deptment of Public Health

PRINCIPAL POSITIONS HELD:

Clinical/Administrative:

1965-66	V.A. Hospital New Orleans, Louisiana	Staff Nurse, Surgical Unit
1966-70	Mease Hospital & Clinic Dunedin, Florida	Staff Nurse & Head Nurse Perinatal Unit; Director of Nursing Inservice
1970-71	Providence Hospital Seattle, Washington	Team Leader & Charge Nurse Surgical Unit
1971-73	University of Washington Seattle, Washington	Staff Nurse & Assistant Head Nurse, Perinatal Unit
1973-75	Alta Bates Hospital Berkeley, California	Nursing Care Coordinator Perinatal Unit

1975-80	Moffitt Hospital, UCSF San Francisco, California	Administrative Nurse III [Head Nurse], Perinatal Unit
---------	---	--

Educational:

1980-86	Moffitt-Long Hospital, UCSF San Francisco, California	Nurse Educator and Clinical Nurse IV Nursing Education and Research
1986-88	Langley Porter Hospital, UCSF	Assistant Director of Nursing Services and Staff Development Director
1988-1991	School of Nursing UCSF	Assistant Clinical Professor, Step IV and HIV Specialty Coordinator

Research:

1991- now ¹⁹⁹⁴	Community Consortium UCSF	Clinical Research Nurse
---	------------------------------	-------------------------

ANCILLARY POSITIONS HELD CONCURRENTLY:

1982-now	Assistant Clinical Professor, Non-Salaried Appointment Dept. of Family Health Care Nursing
1986-1988	Assistant Clinical Professor, Non-Salaried Appointment Dept. of Mental Health and Community Nursing

HONORS AND AWARDS:

1973	Sigma Theta Tau, National Nursing Honor Society
1982	Special Merit Award, UCSF
1983	Nominated for the Robert C. Kirkwood Award, San Francisco Foundation
1986-now	<u>Who's Who In American Nursing</u>
1987	Founders Award, AIDS/ARC Update
1987	National Service Award, in recognition of distinguished service, Biennial Convention Arrangements Committee, Sigma Theta Tau
1988	Book of the Year Award, American Journal of Nursing
1988	September selection, Nursing Book Society
1989	Appreciation Award, for community service as Chair of HIV Task Force, California Nurses Association
1989	Invited by U.S. Public Health Service to invitational workshop: Nursing and the HIV Epidemic: A National Action Agenda
1990	Invited by W.H.O. to represent U.S. nurses at meeting on Professional Education, Istanbul, Turkey
1990	Inducted into American Academy of Nursing

- 1991 Appreciation Award, for community service as Chair of HIV Task Force,
 California Nurses Association

MEMBERSHIPS IN PROFESSIONAL ORGANIZATIONS:

- 1972-1986 Nurses Association of ACOG
1980-1986 Nurse Educators of the Bay Area
1973-now Sigma Theta Tau International
 American Nurses Association
 California Nurses Association
1984-now Women's AIDS Network
1987-now Western Institute of Nursing
 West Bay Hospital Council AIDS Coordinating Committee
 Golden Gate Nurses Association AIDS Interest Group
1988-now Association of Nurses in AIDS Care
 International AIDS Society
 County Community AIDS Consortium
 AIDS Service Providers Association
1989-now Physicians Association for AIDS Care
 American Public Health Association
1990-now American Academy of Nursing

PROFESSIONAL ORGANIZATION ACTIVITIES:

- | | | |
|-----------|------------------------------------|--|
| 1981-1983 | Nurses Association of ACOG | Bay Area Chairperson |
| 1986-87 | Alpha Eta Chapter, Sigma Theta Tau | President-Elect |
| 1987 | Sigma Theta Tau International | Co-Chair, Volunteer Activities,
Biennial Mtg. |
| 1987-89 | Alpha Eta Chapter, Sigma Theta Tau | President |
| 1988-now | California Nurses Association | Chair, HIV Task Force/Committee |
| 1989 | CA Nurses' Association, Region 12 | Delegate to State Convention |
| 1989-90 | Association of Nurses in AIDS Care | Bay Area Co-Chair |
| 1990-now | Women's AIDS Network | Executive Board member
Chair 1990 - 1991 |
| 1991 | CA Nurses' Association, Region 12 | Delegate to State Convention |

SERVICE TO PROFESSIONAL PUBLICATIONS:

- | | | |
|----------|-------------------------------|---------------------|
| 1989-now | American Journal of Nursing | Manuscript Reviewer |
| 1990-now | AIDS Education and Prevention | Manuscript Reviewer |

NATIONAL PRESENTATIONS:

- 1982 Fourth Annual Lesbian and Gay Health Workers Conference / First National AIDS Symposium: Consultant for Several Workshops
1983 Fifth National Lesbian/Gay Health Conference / Second National AIDS Forum; Health Pioneering in the 80's. Speaker, "AIDS 101: Basic Medical and Epidemiological Overview." Workshop Consultant, "Meeting Patient's Needs."

BOOKS:

Lewis, Angie, editor, Nursing Care of the Person with AIDS/ARC, Aspen Publications, 1988.

CHAPTERS IN BOOKS:

Lewis, Angie, "AIDS in Perspective," in Lewis, Angie, editor, Nursing Care of the Person with AIDS/ARC, Aspen Publications, 1988, pp. 1-2.

Lewis, Angie, "Dealing with Issues of Sexuality," in Lewis, Angie, editor, Nursing Care of the Person with AIDS/ARC, Aspen Publications, 1988, pp. 283-286.

Lewis, Angie, "Development of AIDS Awareness: A Personal History," in ^{Inge B.} Corless and ^{Mary} Pittman-Lindeman, AIDS: Principles, Practices, and Politics, Reference Edition, Hemisphere Publications Corporation, 1989, pp. 331-336.

ARTICLES:

Lewis, Angie, "Development of AIDS Awareness: A Personal History," Death Studies, 12:5-6, 1988, pp. 371-379.

Lewis, Angie, "Development of AIDS Awareness: A Personal History," in ^{Inge B.} Corless and ^{Mary} Pittman-Lindeman, AIDS: Principles, Practices, and Politics, Abridged Edition, Hemisphere Publications Corporation, 1987.

Hall, J., Koehler, S., and Lewis, A., "Neuropsychiatric Aspects of AIDS," Seminars in Oncology Nursing, 5:4, November 1989, pp. 276-283.

COMMENTARY:

Lewis, Angie, "Make No Assumptions About AIDS," NURSEWEEK, 2/4/91, p. 1.

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

Angie Lewis,
Private Papers

BERKELEY • DAVIS • IRVINE • LOS ANGELES • RIVERSIDE • SAN DIEGO • SAN FRANCISCO



SANTA BARBARA • SANTA CRUZ

Department of Nursing Services
Division of Education and Research

SAN FRANCISCO, CALIFORNIA 94143

A-14 Plaza

August 10, 1983

Nomination Committee
AIDS/KS Foundation
P.O. Box 14227
San Francisco, CA 94114

To Whom It May Concern:

I have worked with the AIDS situation and with people with AIDS since November 1981, and during that time I participated in the establishment and development of the AIDS/KS Foundation. My participation has, however, been limited due to other AIDS commitments and in some regard due to my frustration with an early lack of clarity regarding the short and long range goals of the organization. I am strongly committed to the avoidance of service duplication and in my initial involvement with the patient services committee, I was very concerned about avoiding the development of services which would overlap those offered by Shanti. I also had, and to some extent still have, concern about the selection of and limited training provided to office staff who have contact with the public. Regardless, I have remained committed to and supportive of the Foundation, frequently serving as a speaker for professional programs, providing informal consultation for Mitch Bart, and supporting the Foundation in meetings and consultations.

I am now at a point where I feel I can best serve the needs of our community, and I use that term in it's broadest sense, by becoming more fully involved in the Foundation through service on the Board of Directors. I feel I not only have expertise but personal involvement/contacts with organizations and individuals which, if I were selected for the Board, would be useful to the Foundation. The following is a summary of those I consider most important:

1. Educational experience, teaching, developing and coordinating workshops.
2. Management experience as a head nurse.
3. San Francisco AIDS Coordinating Committee - I attend on a regular basis.

4. Federation of AIDS Related Organizations (FARD). I am co-representative for San Francisco on the National Steering Committee.
5. Consultation - I receive phone calls and letters from all over the country related to AIDS, and specifically professional education.

Additionally, I have established working relationships with most members of the Foundation staff.

In summary, I feel I have demonstrated my commitment to the development of effective ways in which we may deal with the AIDS crisis and with it's implications for the community and for individuals. I hope you will demonstrate your agreement be selecting me to serve on the Board of Directors for the Foundation.

Thank you.

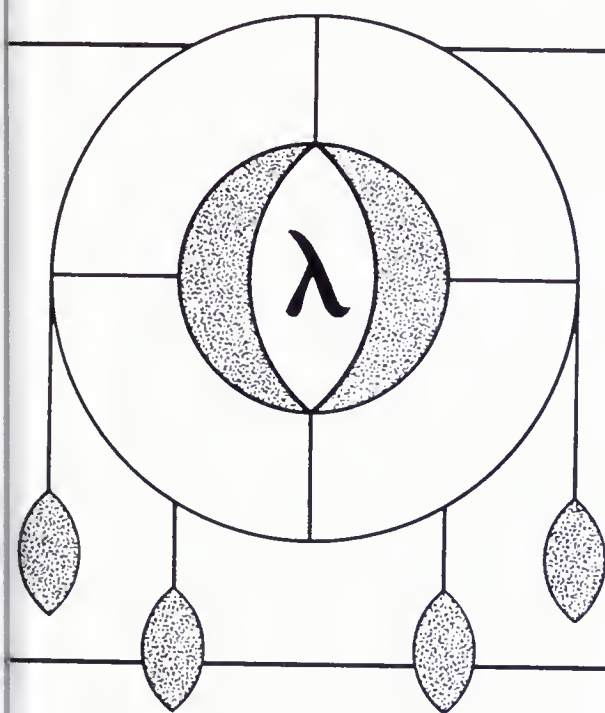
Sincerely,

Angie Lewis, R.N., M.S.N.
Nurse Educator

P.O. Box 9413
Denver, Colorado 80209

Return Postage Guaranteed
Correct Address Requested

Health Pioneering in the 80's



Health Pioneering in the 80's

June 9, 10, 11, 12 • 1983
Denver, Colorado

The Fifth National Lesbian/Gay Health Conference

WHAT: The theme of the conference is "HEALTH PIONEERING IN THE 80'S." Speakers, workshops and sessions will focus on lesbian and gay participation in health, including health delivery, definitions of health, health research and health politics. Sessions will also highlight the lesbian and gay role in creating a new paradigm of health delivery and philosophy. The conference includes the SECOND NATIONAL FORUM ON ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS), the annual meeting of the American Association of Physicians for Human Rights (AAPHR) and organizational time for national lesbian and gay health groups.

WHO: The conference is being sponsored by the National Gay Health Education Foundation, Inc., the American Association of Physicians for Human Rights and the Gay and Lesbian Health Alliance of Denver. The conference is designed for lesbian and gay healthworkers and those interested in services by and for lesbians and gay people.

WHERE: The conference will take place at the Executive Tower Inn located at 1405 Curtis Street, Denver, Colorado 80202. This luxury hotel/conference facility is located in the heart of downtown Denver.

WHEN: June 9, 10, 11, 12, 1983. The general conference will begin Thursday evening and continue until noon Sunday. The Second

National Forum on AIDS will begin Thursday morning prior to the start of the general portion of the conference.

WHY: This conference will be the primary place where lesbian and gay healthworkers will meet to address the health and survival issues facing our community at this time. It will be a unique opportunity to educate each other, to share resources and to network on a national basis. As Margaret Mead wrote, "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it is the only thing that ever has." A very special and exciting conference awaits you in Denver.

Conference Overview—Health Pioneering in the 80's

The following are some of the themes to be addressed at the conference:

- Gay Holistic Health
- Lesbian/Feminist Health Issues
- Lesbian and Gay Aging: Realities and Challenges
- The Health Needs of Lesbian/Gay Youth
- Guidelines for Healthy Gay Male Sexual Activity
- Counseling and Therapy Issues
- Alcoholism Services
- Alternative Parenting
- Coming Out Professionally
- The Impact of AIDS on Gay Male Sexuality
- Creating a Gay Community Service Center
- Food Addiction and Sexuality
- Racism in the Lesbian and Gay Community
- Chemical Dependency in the Lesbian/Gay Community
- Sexually Transmitted Diseases
- Stress Reduction and Relaxation Techniques
- Health and Politics
- Hepatitis B Vaccination Strategies
- Stages of Gay Male Relationships
- Artificial Insemination
- Alcohol Abuse amongst Lesbians and Gay Men
- Relationships and Intimacy
- Alcoholism and Incest
- Clinical Update on AIDS
- The Ideal Women's Therapy Program
- Organizing and Networking

address "Confronting Homophobia, Racism and Sexism in the 80's."

KAREN CLARK, Minnesota state legislator; co-founder Minneapolis Medical Committee for Human Rights, Women's Counseling Services, Westside People's Health Center. Ms. Clark serves on various house committees (health and welfare) and has fought continuously for the basic human rights of Native American Indians, Blacks, Women, and Lesbians and Gays in Minnesota. She has been involved in numerous political organizations and will speak on "Gay and Lesbian Health; A Political Issue."

JEROME PERLINSKI, Secretary General of the International Teilhard Foundation, author of **HOPE: A Four Letter Action Verb**, **Austere Passions** (discussions on personal transition to a global age in politics, economics and art), **Divine Bodies** (explorations in spirituality and sexuality) and the recent **Advocate** article "Gays and the New Age: As the Paradigm Shifts." Dr. Perlinski will address "Gays and the New Age."

VIRGINIA M. APUZZO, former Assistant Commissioner for Operations, New York City Department of Health; Coordinator, National Gay Task Force effort to obtain a Gay Rights Plank in the Democratic Party; Executive Director of the National Gay Task Force. Ms. Apuzzo will address "Health Pioneering in the 80's."

SECOND NATIONAL FORUM ON AIDS:

One of the most successful aspects of the first National Health AIDS Forum was its focus on a dialogue of decision maker and primary health care providers. The 2nd National Health AIDS Forum will continue this emphasis, along with that of long-range planning.

The AIDS forum is specifically designed for

those currently involved and contemporary with AIDS issues.

Participants will actually be involved in dealing with the enhancement of the AIDS efforts on political, socio-cultural, and patient care levels.

The following is a tentative list of workshop topics planned for the forum:

- AIDS Medical Update "State of the Art"
- Public Policies
- Examination of Epidemiology
- Infection Control and Risk Reduction Guidelines
- Meeting Patient Needs
- AIDS Network Development
- Political Strategies
- Creating Positive Changes in Sexual Mores

If you wish to attend the forum, check the registration form. Further information will be sent as it becomes available.

AAPHR MEDICAL SYMPOSIUM

The American Association of Physicians for Human Rights will be conducting a symposium in conjunction with the health conference and the AIDS Forum. The Symposium will occur over Thursday, Friday and Saturday and will encompass 12 hours of formal and panel presentations. Topics to be covered include the current state of medical and scientific knowledge about AIDS: Hepatitis B and the safety and efficacy of the recently introduced vaccine; Sexually Transmitted Diseases, risk reduction and sexual ethics; aspects of gay coupling; and issues in lesbian health care. C.M.E. Credit has been applied for. The Annual meeting of the AAPHR membership will occur Saturday evening after the Symposium. Please check the appropriate box on the registration form to receive further information (detailed schedule, speakers, additional registration costs) for the symposium.

KEYNOTE SPEAKERS

BERNICE GOODMAN, M.S., A.C.S.W., L.S.W., President-elect of the National Gay Health Education Foundation, Inc., Founding Chairperson of the National Association of Social Worker's Task Force on Lesbian/Gay Issues, author of **Confronting Homophobia, The Lesbian: A Celebration of Difference**, and **Where Will You Be? The Professional Oppressions of Gay People: A Lesbian/Feminist Perspective**. Ms. Goodman will

Registration

NAME _____ PROFESSION _____
 PHONE (day) _____ ADDRESS _____ ORGANIZATIONS _____
 (eve) _____

REGISTRATION FEES [Covers the cost of attending all workshops and/or the Second National AIDS Forum]

- ☐ \$50.00 Regular (before May 8, 1983)
☐ \$35.00 Student/Over 65 (before May 8, 1983) Send Proof of Full-time student status.
☐ DEDUCT \$10 FROM REGISTRATION FEE IF YOU STAY AT THE EXECUTIVE TOWER INN.
☐ \$25.00 ADDITIONAL charge if Registering after May 8, 1983.
☐ \$25.00 ADDITIONAL Charge if attending the Annual Banquet/Meeting of the American Association of Physicians for Human Rights [SATURDAY EVENING]
☐ I would like to attend the noon luncheon/reception Friday, June 10. Entertainment will be provided. Open to all conference participants. Additional \$7.00
☐ \$_____ Total Registration fee enclosed. Make check or money order payable to N.G.H.E.F. Inc. or The Health Fund

For more information, contact co-chairs Dan Pfeiffer (714-494-0293) or Fran Miller (415-653-3724), or write Health Pioneering in the 80's, P.O. Box 9413, Denver, Colorado 80209

CONFERENCE INFORMATION

- ☐ I will be attending the Second National Forum on AIDS. Please send me additional information.
☐ I will be attending the General Health Conference workshops: Health Pioneering in the 80's
☐ I will be attending the MEDICAL SYMPOSIUM of the American Association of Physicians for Human Rights. Please send me information about AAPHR planning as it becomes available.
☐ I am interested in C.M.E. or C.E. Credit should it be available. (The cost of such credit is not included in the Registration Fee) Please send me further information as it becomes available.

Accommodations

Executive Tower Inn • 1405 Curtis Street • Denver, Colorado 80202

This resort hotel in downtown Denver is located adjacent to the Denver Center for the Performing Arts and Larimer Square. All conference workshops and seminars will take place here. Hotel accommodations include use of a complete athletic club, pool, handball and tennis courts (available on site).

Accommodations are available to conference participants at a special rate of \$7.00 + tax per night for a single or double room. In addition, there is a reduced registration fee if you stay at

the Executive Tower Inn.

Make Payable To:
N.G.H.E.F. Inc. or The Health Fund.

Mail To:
HEALTH PIONEERING IN THE 80's
P.O. Box 9413
Denver, Colorado 80209
(303) 777-9530

This form may be reproduced for additional registrations.

- ☐ I am interested in accommodations at the Executive Tower Inn.
 _____ Wed. _____ Thurs. _____ Fri. _____ Sat. Night(s)
☐ Single Room \$47.00 + tax/night
☐ Double Room \$23.50 + tax/night per person
 Name of second occupant if known: _____
☐ I would like to be matched with someone (_____ smoker _____ non-smoker) for Double Occupancy
☐ I would like accommodations in a private residence if available.
☐ I am making other arrangements.
 Enclosed is a check or money order for
 \$_____ Registration Fees
 \$_____ Hotel Deposit required
 \$47.00/Single, \$47.00/Double,
 \$23.50/Individual
 \$_____ Total

Conference Schedule

Wednesday, June 8, 1983 (evening)
 6:00-10:00 Registration for AIDS Forum attendees
 Hospitality/Information room availability

Thursday, June 9, 1983
 6:30- 6:00 Second National Forum on AIDS
 7:00- 7:30 Registration for Health Pioneering in the 80's
 10:00-10:00 Welcome, Opening Address, Keynote Speakers

Friday, June 10, 1983

8:30-12:00 Second National Forum on AIDS continues; Health Pioneering in the 80's Workshops
 12:00- 2:00 Lunch (optional lunch/reception with entertainment planned at an additional cost of \$7.00)
 2:00- 6:00 Second National Forum on AIDS continues; Health Pioneering in the 80's Workshops
 8:00 Entertainment to be provided

Saturday, June 11, 1983

8:30- 6:00 Health Pioneering in the 80's Workshops
 Evening Entertainment to be arranged
 AAPHR Banquet/Annual Meeting (additional cost of \$25)

Sunday, June 12, 1983

9:00-10:00 Presentation of "Jane Addams-Howard Brown Award" for contribution to the gay community
 To: National Association of Gay Alcoholism Professionals (Emily McNally and Dana Finnegan will address the assembly on Alcoholism in the Lesbian/Gay Community)
 To: National Coalition of Gay Sexually Transmitted Disease Services (Mark Behar will address the assembly)
 10:00-12:00 Report from the AIDS Forum Closing Address/Keynote Speakers



DAVID JOSEPH EDD	DAN PFEFFER	JEANNE BRIDGEMAN EDD, RN	PAUL A. PERROW, JR. M.D.	JEFFREY RICHARDS	MARTIN P. LEVINE M.A.
EDWARD GOODMAN PH.D.	ALICE L. MESSING M.A.	ERNEST L. LAFERRE M.S.N., RN	BERNICE GOODMAN M.S., ACSW	DEAN PIERCE C.S.W.	FRANK GREENBERG M.D.

April 19, 1983

Dear Presenter:

We are pleased to inform you on the acceptance of your workshop proposal(s) for the FIFTH NATIONAL LESBIAN/GAY HEALTH CONFERENCE. Enclosed you will find a program description of your workshop. Please send a written confirmation of your participation no later than May 5, 1983 to Dan Pfeffer, 347A Mermaid, Laguna Beach, CA 92651. Include any special needs you may have for your presentation, including need for audio-visual equipment if not already stated.

We are also enclosing a registration brochure to be completed and returned to HEALTH PIONEERING IN THE 80'S, P.O. BOX 9413, Denver, CO 80209. If you have already sent us your registration form, please pass this brochure on to a colleague. Due to financial constraints at this time, we are not able to waive the registration costs. We have instituted a sliding scale fee from \$35.00 to \$50.00 for presenters. Please pay according to your income. We are also instituting a limited scholarship fund to supplement registration fees. Please contact Fran Miller (415-653-3724) or Dan Pfeffer (714-494-0293) for more information.

We look forward to seeing you in Denver in June. Your participation and leadership in the conference will make it a success. Please feel free to call us with any concerns you might have between now and June.

In Community,

Dan Pfeffer Fran Miller
Conference co-coordinators

FIFTH NATIONAL LESBIAN / GAY HEALTH CONFERENCE
HEALTH PIONEERING IN THE 80's

ALCOHOLISM AND OTHER DRUG DEPENDENCIES: A NATIONAL FORUM TO ADDRESS INCIDENCE, ISSUES, and RESOLUTIONS. Sponsored by the National Association of Gay Alcoholism Professionals (NAGAP), Dana Finnegan, Ph.D., C.A.C. and Emily McNally, M.Ed., C.A.C., NAGAP National Coordinators. NYC. (1½ Hrs.)

This workshop is intended to provide lesbian and gay healthworkers from across the country the opportunity to share their experience, knowledge, questions and concerns about alcoholism and other drug dependencies. This forum will act as a catalyst for a major effort to address this health problem.

"COMING OUT" AS A CRITICAL PHASE IN IDENTITY FORMATION FOR LESBIANS.

Susan I Frankel, M.S.W., A.C.S.W., Director of Training, Institute for Human Identity, NY. The process of "coming out" as lesbians will be discussed as a healthy development of sexual identity formation. Focus will be on the emotional, cognitive and social changes one undergoes during "coming out." (1½ Hrs.)

The Development of Lachisis Center for Healing, Mnpls. Panel includes: Jean Eckerly, M.D., Jan Dickson, P.A., Valerie Ohanian, homeopathic practitioner; Nancy Grossard, R.N., Carol La Favor, R.N., Barbara Wiener, massage therapist, Jan Owens, Medical Assistant, Herdis Brown, office manager. The Centers health team uses a variety of techniques and tools to help restore health in a safe and natural way. The panel will discuss the conception of the center, how it was organized, and philosophy of staff. (2 hrs.)

AIDS-THE HOUSTON PREVENTIVE MENTAL HEALTH STATEMENT. Bryan Guiot, Ed.D. candidate., William A Scott, M.S.W., Gary Treese, M.S.W., Walter Cadenhead, M.A., Houston. This workshop will discuss the development of the Houston Preventive Mental Health Statement and its integration within the gay community. (3 hrs.)

AIDS 101: Basic Medical and Epidemiological Overview of AIDS.

Angie Lewis, RN, MS, Nursing Education and Research, U.C.S.F. and Steve Follansbee, M.D., Infectious Diseases, UCSF., San Francisco, California.

Presentation of current information about AIDS and the specific cancers and opportunistic infections associated with AIDS; current epidemiologic data; common treatment modalities; implications for patient care; infection control guidelines. (1½ hrs)

(A SLIDE PROJECTOR WILL BE PROVIDED) *(and opaque projector)*

SELF-HELP FOR SEX: FEMINISTS REDEFINE THE CLITORIS.

The Federation of Feminist Women's Health Centers, L.A., CA. (1½ hrs.)

This presentation will show through photographs and detailed illustrations that feminist help research is essential towards women understanding our sexual anatomy and defining our sexuality and sexual needs.

(A SLIDE PROJECTOR AND OPAQUE PROJECTOR WILL BE PROVIDED)

UNDERSTANDING AND FIGHTING ANTI-SEMITISM: TOOLS FOR SPIRITUAL AND MENTAL HEALTH (1½ hrs.)
Barbara Wiener M.A. Mnpls., MN.

This workshop will focus on the ways in which anti-semitism is an additional oppression to Jewish Gays and Lesbians. Discussion will include ways in which Jews and non-Jews experience anti-semitism in their lives, exploring ways and ideas for fighting back. Open to all interested people.

To: Marilyn Chow

From: Angie Lewis

Date: June 6, 1989

I believe my most important contribution to the AIDS struggle has been the role I have played as a bridge builder. By this I mean that I try to connect individuals and agencies and encourage them to work together in a complementary manner in order to accomplish common goals whether they be educational, clinical, public health, or whatever. I also take advantage of opportunities to talk with others about the situation and encourage them to become proactively involved. I hate to see "re-invention of the wheel" so I not only encourage others to share freely of themselves and their work, I make an effort to model that behavior. For example, I recently established a periodic meeting for nurses doing HIV research, and although I know they can't attend, my mailing list includes nurses from many states whom I've met at meetings or my correspondence. I want them to get to know and learn from each other.

Education is one means by which I have helped build bridges. In the fall of 1981 I initiated planning for what I believe was the first conference presented in the nation for health care professionals other than physicians. In fact, we purposefully did not include any physicians on the program, instead choosing to concentrate on presentations by nurses, social workers, nutritionists, and respiratory therapists who provided direct care at the bedside. We did include a PWA panel and I closed the day with a presentation on "Caring for Ourselves." This early program served as a model for an educational approach which was multidisciplinary, included PWA's, and helped build linkages between clients and care givers.

Serving as a role model is another area where I feel I have had an impact. In the very early days, I modeled touching persons with AIDS, for example purposefully hugging PWA's after public presentations. Also, during those times, and throughout the years, I included PWA's in planning educational programs and suggested (demanded??) a PWA presentation as part of educational programs with which I've been associated. Advocacy for PWA's in program planning, establishment of policy, etc. is a role which I assumed very early in the epidemic. Whether as a Board member, a program presenter or coordinator, or simply as a citizen, I used my status as a nurse to advocate for inclusion of PWA's as active participants in presenting their view of the world and in determining the care which they would receive. The role of PWA's in educational programs was the topic of a poster session which I presented at NIH at their first nursing AIDS conference in 1983.

Another area where I think I may have made a difference is in encouraging care providers to take care of themselves and giving them "permission" to do so. I consciously try to make others feel good about their excellent work and I make a point of giving them acknowledgement for their work, ideas, and contributions. I often talk about the need to support each other in taking time off or at least time out in order to nurture ourselves and I maintain an empathic and supportive attitude toward those who elect to step back. Another aspect of caring for oneself is experiencing personal and professional growth and moving along a career path toward greater challenge and leadership. I'm currently working with

a group of AIDS nursing leaders in San Francisco and helping them prepare for application to graduate study at U.C.S.F. Their successful completion of these programs will not only enhance their personal growth, but will help provide our profession with the first generation of AIDS leaders.

Finally, I have consciously chosen to be a public role model for gay and lesbian individuals. I spent many years hiding my sexual orientation and only gradually, and painfully, came to accept myself as a lesbian. Had it not been for the reality of AIDS and its' impact on the gay and lesbian community, I would probably still have only one foot out that closet door. AIDS would not allow me to do that; only by being clear and honest about my sexual orientation could I could counter stereotypes and provide explanations which would help build bridges between care providers and clients.

Being asked to write a statement of your personal contributions is a real challenge!! I hope this meets your needs, however I'll be happy to provide any other requested information. There are also any number of nurses who could provide further support, e.g. Cliff Morrison, Rita Fahrner, Helen Schietinger, and Laurie Hauer. As background, I have enclosed two letters and a copy of a book chapter I wrote. The letters support my contributions as a "bridge builder" and a role model. The book chapter describes my early involvement in AIDS work. I believe I was the first person to visit patients at UC in an attempt to provide emotional support, and since we were among the first institutions to have patients that means I was among the first nurses in the country to begin to purposefully work with persons with AIDS.

Future ANA Meetings

House of Delegates, July 23-25, 1985, Kansas City, Missouri
 55th Convention, June 13-19, 1986, Anaheim, California
 56th Convention, June 10-16, 1988, Louisville, Kentucky
 57th Convention, June 15-21, 1990, Boston, Massachusetts

Our hosts for the 1984 ANA convention are the members of the Louisiana State Nurses Association. More than 200 registered nurses and students from Alabama, Louisiana, and Mississippi have volunteered their time. Volunteers are readily identifiable by their brightly colored Mardi Gras ribbons (green, gold, and purple). ANA is most appreciative of all their time and assistance.

Please remember that smoking is not allowed in program sessions. This regulation was adopted by the ANA Board of Directors before the 1974 convention upon the recommendation of the Division on Medical-Surgical Nursing Practice and has been carried out at every ANA convention since.

Program

54th Convention
 June 22-28, 1984 / New Orleans, Louisiana

Theme: Challenges and Choices



American Nurses' Association
 2420 Pershing Road
 Kansas City, Missouri 64108

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Welcome to ANA's 1984 convention! This convention program book is your guide to the meetings and other activities that address the '84 convention theme, "Challenges and Choices."

The first section of the book provides you with general information about the convention site and operating procedures. It also gives information about some of the many activities happening during the convention. Up front is an overview of those activities. In addition, in this section you will find the agenda and meeting schedule of the House of Delegates, the proposed standing rules for the house, campaign regulations for ANA elections, information on hearings and forums, and instructions for continuing education contact hour credit for approved programs.

In the second section is detailed information on the convention programs, which are listed in chronological order.

Information about the exhibits at Convention '84 is to be found in the next section. The section includes a diagram of the exhibit area and a listing of the exhibitors, along with descriptions of the products and services featured in the exhibit booths.

The exhibit section is followed by an index of advertisers in this book. Last is an index of program participants.

CONVENTION '84 OVERVIEW

FRIDAY, JUNE 22

8:00 a.m.-5:00 p.m. *General and Delegate Registration*
6:00 p.m. *Opening Night Ceremony*
8:00 p.m. *All-Participants Party*

SATURDAY, JUNE 23

8:00 a.m.-10:00 a.m. *Business Meetings*. Council of Clinical Nurse Specialists, Council on Nursing Home Nurses, Council of Specialists in Psychiatric and Mental Health Nursing
8:00 a.m.-10:30 a.m. *Business Meetings*. Council on Intercultural Nursing, Council on Nursing Administration, Council of Primary Health Care Nurse Practitioners, Council of High-Risk Perinatal Nurses
8:00 a.m.-5:00 p.m. *General and Delegate Registration*

9:00 a.m.-5:00 p.m. *Symposium* Future Nurse Researchers
10:30 a.m.-12:30 p.m. *Business Meetings*. Division on Maternal and Child Health, Nursing Practice, Division on Psychiatric and Mental Health Nursing Practice, Council on Continuing Education, Division on Gerontological Nursing Practice, Division on Medical-Surgical Nursing Practice, Council of Nurse Researchers
10:30 a.m.-4:00 p.m. *Business Meeting*. Division on Community Health Nursing Practice
11:00 a.m.-5:00 p.m. *Exhibits Open*

12:30 p.m.-1:15 p.m. *Forum*. Proposed Council on Computer Applications in Nursing
2:00 p.m.-3:45 p.m. *Plenary Session*. The Challenge of Looking at Tomorrow Through Today's Eyes

4:00 p.m.-5:45 p.m. *Concurrent Program Sessions*. Main Societal Issues Confronting Community Health Nursing Practice. Is Nursing's Self-Regulating Responsibility Being Eroded? Impact of High-Tech Technology Communication on the Nursing Profession Now and in the 21st Century. Minority Unification of the Health Care System. Innovative Provisions in SNA Collective Bargaining Agreements. The Quality Choice: Accreditation of Continuing Education in Nursing. Perspectives on Long-Term Care: Building Networks Through Common Concerns. Application of Research to Improve Clinical Practice. A Holistic Approach to Patient Enhancement: Its Impact on Adolescent Health. Implementing Nursing Research to Improve Ambulatory Care

6:00 p.m.-7:45 p.m. *Plenary Session*. Follow-Up to the Strategy Workshop on Nurse Practitioner Issues

6:00 p.m.-7:45 p.m. *Forum*. Proposed Council on Medical-Surgical Nursing Practice

6:00 p.m.-8:00 p.m. *Forum*. Innovative Models for Delivery of Community-Based Nursing Service

SUNDAY, JUNE 24

8:00 a.m.-11:00 a.m. *Reference Committee Hearings*
8:00 a.m.-5:00 p.m. *General and Delegate Registration*
9:00 a.m.-10:45 a.m. *Plenary Session*. Methodological Strategies for Validating the Nursing Diagnosis Classification System
9:00 a.m.-10:45 a.m. *Council Formation Interest Groups*
9:00 a.m.-10:45 a.m. *Special Interest Groups*. Private Practice, Nurse Educators

9:00 a.m.-5:00 p.m. *Exhibits Open*
11:00 a.m.-12:45 p.m. *Plenary Session*. The Choices Nurses Must Make

1:00 p.m.-2:45 p.m. *Forum*. Revision of Interpretive Statements to Code for Nurses

1:00 p.m.-2:45 p.m. *Special Interest Groups*. Substance Abuse, Child and Adolescent Practice, Psychogeriatric Practice

1:00 p.m.-3:00 p.m. *Plenary Forum*

1:00 p.m.-3:00 p.m. *Forum*. Organ Donation and Transplantation

3:00 p.m.-4:45 p.m. *Business Meeting*. Advocates for Child Psychiatric Practice in conjunction with Council of Specialists in Psychiatric and Mental Health Nursing

3:00 p.m.-5:00 p.m. *Plenary Forum*

5:00 p.m.-6:45 p.m. *Concurrent Program Sessions*. Managing the Problems of Impaired Professional Practice: Family Violence: Nursing Roles in Intervention and Formulation of Health Policy. Evaluating the Clinical Nurse Specialist: Performance Appraisal, Self-Assessment, and Peer Review. Magnet Hospitals: Attraction and Retention of Professional Nurses. Cultural Diversity: An Enrichment Mechanism. Long-Term Care for Chronically Ill Aged: New Dimensions and Challenges for Nursing Home Nurses. Meeting the Challenges of Tomorrow: Implementing the Revised Standards for Continuing Education. Nursing Research: Its Impact on Public Policy. Emerging Issues in Health Care Bargaining. Prospective Pricing: Implications for the Delivery of Nursing Services

5:00 p.m.-7:00 p.m. *Reference Committee Hearings*

MONDAY, JUNE 25

8:00 a.m.-9:00 a.m. *Delegate Registration*

8:00 a.m.-5:00 p.m. *General Registration*

9:00 a.m.-1:00 p.m. *House of Delegates*

9:00 a.m.-3:00 p.m. *Exhibits Open*

1:00 p.m.-2:00 p.m. *Legislative Briefing*

2:00 p.m.-3:45 p.m. *Concurrent Program Sessions*. Developing Contacts with Political Officeholders (Part I: Lobbying Techniques). Challenges and Choices in Membership Development. Functional Health Patterns as a Basis for Nurse

HOTEL LISTING AND MAP



Hotel Location Key

- * A. Marriott
- * B. Sheraton
- C. Hyatt Regency New Orleans
- D. New Orleans Hilton
- E. International
- F. Monteleone
- G. Le Pavillon
- H. Ramada
- I. Days Inn
- J. Fairmont
- K. Royal Sonesta
- * Convention Headquarters Hotels

Convention '84 Overview

ive Committee Management at the Grass-Roots Level. Meeting the Challenge of the Nuclear Age: The Nurse's Role. Information Resources for Nurses: Challenges and Choices. Computers in Nursing Education: Challenges and Choices. History of Regional Associations and Their Impact on Research

1:00 p.m.-2:45 p.m. Concurrent Program Systems. Challenges and Choices in High Blood Pressure Control. The Nurse's Role in Detection, Treatment, and Long-Term Management. Biofeedback Therapists: Nurses As a Natural History and Continuing Education in Nursing Process. Nursing Diagnoses. Current and Future Challenges

3:00 p.m.-4:45 p.m. Concurrent Program Systems. Staff Grid: Creating a Program for Coping. Development of a Support System for Grieving Parents: A Challenge for the Obstetrical Nurse. Accepting the Challenge of Reproductive Advocacy and Making Your Choices Known. Nursing Autonomy and High-Tech Health

3:00 p.m.-8:00 p.m. House of Delegates
5:00 p.m.-6:45 p.m. Program Session. Computerized Information Systems: Challenges and Choices

WEDNESDAY, JUNE 27

7:00 a.m.-11:00 a.m. Delegate Voting
8:00 a.m.-1:00 p.m. Delegate Registration
8:00 a.m.-5:00 p.m. General Registration
9:00 a.m.-10:45 a.m. Concurrent Program Systems. Leading Nursing in China: Humanities and Nursing: An Ambiguous Relationship. Estimating the Nation's Nurse Supply. How Many Nurses Are There? The Rural Clinical Nurse Placement Center: Addressing the Needs of Registered Nurse Maldistribution in Rural Areas. Achieving Competency in a Graduate-Level Three-Pronged Oncology Care Curriculum. A Gift from the Heart: The Life Review in Health Revolution of the Final Developmental Stage

11:00 a.m.-12:45 p.m. Concurrent Program Systems. Nurses Model Health: Social Support Skills. A Peer Assistance Program for Chemically Dependent Nurses. What We Demand from Our Food Supply: The Present and Future Challenge. Licensure in Nursing: Patient Care Information and Education: The Team Approach. Nursing's Role in Preventing Nuclear War

1:00 p.m.-2:45 p.m. Concurrent Program Systems. Meeting the Challenge of Waiting for Publication. Impact of Medicaid and Medicare Policies on the Aged and on Nursing, Nursing and Radiation Safety. Nurses Assisting Nurses: A Model Program Addressing Nurse Impairment. Computer-Assisted Patient Care Management. The Health Care Delivery System: Issues and Trends in the '80s

1:00 p.m.-7:00 p.m. House of Delegates

THURSDAY, JUNE 28

7:00 a.m.-8:00 a.m. Delegate Registration
8:00 a.m.-12:00 noon. General Registration
8:00 a.m.-1:00 p.m. House of Delegates

ing Diagnosis. Creative Teaching Strategies for Adult Learners. Gerontological Nursing Practice in the 21st Century: A Challenge for Change. Current Legal Challenges to Nurse Practitioners. Application of Interdisciplinary Concepts to Nursing Practice. The Medicare Crisis: Issues and Options. Organized Nursing's Role in the Voluntary Accreditation Process (JCAH). Challenges and Choices. Design and Implementation of Clinical Ladders for Perinatal Nurses

4:00 p.m.-5:45 p.m. Concurrent Program Systems. Developing Contacts with Political Officeholders (Part 2: Campaign Activities). Abuse of the Older Adult Within the Family System. Innovative and Cost-Effective Approaches in Psychiatric and Mental Health Nursing Practice. Acquired Immune Deficiency Syndrome: Nursing's Responsibility. Provision of High-Quality School Health Services. Emerging Values for the '80s: The Implications for Organized Nursing Services. American Nurses Foundation Grants Program: A Choice for Nurse Researchers. The Role of the Professional Nursing Organization in an Information Society: Meeting the Challenges. Cultural Diversity: An Enrichment Mechanism. Primary Prevention Through Perinatal Care and Mental Health Intervention for High-Risk Families. Nursing and Computing: A Dilemma for the Future

6:00 p.m.-7:15 p.m. Concurrent Program Systems. Strategies for Change in Health Care Delivery. Allocation of Nursing Resources in Acute Care Settings in an Era of Cost Containment. Expanding Research Horizons: Obtaining Funding from the Private Sector. Ethical Issues in Maternal/Infant/Neonatal Care. Future Perspectives in Psychogeriatric Nursing Practice and Research. Building Community Recognition in Health Promotion Programs: A Model Reinforcement by Third Parties for Services by Nurses. Professional Practice for Nurse Administrators in Long-Term Care Facilities. Violence: A Phenomenon of Conscience Society

7:00 p.m.-9:00 p.m. Hearing on Emergency Preparedness
8:00 p.m.-9:45 p.m. Program Session. International Issues: Challenges for Nursing

TUESDAY, JUNE 26

8:00 a.m.-9:00 a.m. Delegate Registration
8:00 a.m.-5:00 p.m. General Registration
9:00 a.m.-10:45 a.m. Concurrent Program Systems. The Lagomorph Curriculum: Accessible Higher Education for Registered Nurses Through the Statewide Nursing Program. A Model for Health Care Delivery in Rural Areas. Indian Health Service: Maximizing Choices by Meeting Cultural Challenges of Health. The Historical Basis of Clinical Nursing in the United States. Annual Review of Nursing Research Series: Its Value to Practicing Nurses, Nurse Administrators, Faculty Students, and Researchers

9:00 a.m.-1:00 p.m. House of Delegates
9:00 a.m.-5:00 p.m. Symposium. Future Nurse Researchers
11:00 a.m.-12:45 p.m. Concurrent Program Systems. A Challenge for Nursing Leaders: Ethics

Moderator: Edna Stilwell, Ph.D., R.N.C., Coordinator, Gerontological Nursing Graduate Program, University of Maryland, Baltimore, Md.; Member, Executive Committee, Division on Gerontological Nursing Practice

Presenters

Cornelia Beck, Ph.D., R.N., Associate Dean, Graduate Program, College of Nursing, University of Arkansas for Medical Sciences, Little Rock, Ark.
Linda R. Phillips, Ph.D., R.N., Assistant Professor, College of Nursing, University of Arizona, Tucson, Ariz.

Objectives

At the conclusion of this session, participants will be able to (1) discuss the types and incidence of neglect and/or abuse of the aged, (2) review several explanations of the dynamics underlying neglect and/or abuse of the elderly, and (3) describe the use of nursing process in neglect and/or abuse of the elderly.

4:00 p.m.-5:45 p.m., Mardi Gras E, New Orleans Marriott Hotel

Innovative and Cost-Effective Approaches in Psychiatric and Mental Health Nursing Practice

2.1 contact hours, N035. Sponsor: Division on Psychiatric and Mental Health Nursing Practice

Moderator: Eleanor White, M.S., R.N., School of Nursing, Duke University, Durham, N.C.; Chairperson, Executive Committee, Council of Specialists in Psychiatric and Mental Health Nursing

Presenters

Mattreen Chaisson-Stewart, Ph.D., R.N., Behavioral Health Specialist and Consultant, Phoenix Veterans Administration Medical Center, Phoenix, Ariz.
Doris K. DeVincenzo, Ph.D., R.N., Associate Professor, Lienhard School of Nursing, Pace University, Pleasantville, N.Y.
Barbara J. Evans, R.N., Nursing Supervisor, Mendota Mental Health Institute, Madison, Wis.

Objectives

At the conclusion of this session, participants will be able to (1) describe changes (psychological, social, environmental) that may result from a nursing home residents' environment committee, (2) assess the role of nurses in a program of assertive community treatment (PACT) for the chronically mentally ill, and (3) identify advantages and limitations in providing primary nursing care in a prison setting.

4:00 p.m.-5:45 p.m., Bissonet Room, New Orleans Marriott Hotel

Acquired Immune Deficiency Syndrome: Nursing's Responsibility

2.1 contact hours, N036. Sponsors: Council on Intercultural Nursing, Division on Psychiatric and Mental Health Nursing Practice, Council of Specialists in Psychiatric and Mental Health Nursing, Division on Community Health Nursing Practice

Moderator: David Waldron, R.N., Philadelphia, Pa.; Secretary, Cabinet on Human Rights

Presenters

Bobbi Campbell, B.S.N., R.N., AIDS/Gay Health Care Consultant, San Francisco, Calif.
Angie Lewis, M.S.N., R.N., Nurse Educator, Department of Nursing Education and Research, University of California-San Francisco, San Francisco, Calif.

Objectives

At the conclusion of this session, participants will be able to (1) identify three nursing interventions that will assist the person with AIDS in handling his or her biophysical responses to AIDS and/or its treatment, (2) contrast the psychosocial needs of the newly diagnosed AIDS patient with those of the chronic patient, and (3) identify ways in which the nurse can help the person with AIDS to act autonomously in decision-making related to his or her health care.

4:00 p.m.-5:45 p.m., La Galerie 6, New Orleans Marriott Hotel

Provision of High-Quality School Health Services

2.1 contact hours, N037. Sponsor: Division on Community Health Nursing Practice

Moderator: Judith Sullivan, Ed.D., R.N., F.A.A.N., Professor and Head, Department of Public Health Nursing, College of Nursing, University of Illinois, Chicago, Ill.; Member, Executive Committee, Division on Community Health Nursing Practice

Presenters

Ruth R. Hutchison, M.P.H., R.N.C., Associate Professor, College of Nursing, Seton Hall University, South Orange, N.J.
Georgia P. Macdonough, M.A., R.N., C.S.N.P., School Health Consultant, Arizona Children's Hospital, Tempe, Ariz.
Eleanor Thelander, B.S.N., R.N., White Bear Lake, Minn.; Retired

Objective

At the conclusion of this session, participants will be able to relate ANA standards of school nursing practice to the provision of cost-effective nursing care in schools.

4:00 p.m.-5:45 p.m., Rooms 4 and 5, Rivergate Convention Center

Emerging Values for the '80s: The Implications for Organized Nursing Services

2.1 contact hours, N038. Sponsor: Council on Nursing Administration

Moderator: Karen Hildebrandt, M.S.N., R.N., Assistant Administrator and Director of Nursing, Pocatello Regional Medical Center, Pocatello, Idaho; Chairperson, Executive Committee, Council on Nursing Administration

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